Physical and psychological problems experienced and coping strategies used by heart transplant recipients after their operation.

Evridiki Kaba

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Department of Nursing and Midwifery Studies
University of Glasgow

ProQuest LLC.
789 East Eisenhower Parkway
P.O. Box 1346
Ann Arbor, MI 48106 – 1346

Abstract

This study is aimed at discovering the basic psychological problems and coping strategies used by heart transplant patients. In addition an important goal is the generation of a theory based on the data collected from interviews with patients. The consequences of the study is to provide nurses with the necessary information to help patients make the maximum use of their existing coping strategies and in the case of ineffective patterns to help them change to more effective ways of dealing with their problems.

Forty two heart transplant recipients who had undergone their operation in Royal Infirmary of Glasgow provided the sample for the present study. The primary means of data collection was through informal, in-depth and unstructured interviews.

The research approach was based on Glaser and Strauss's principles for the generation of grounded theory and the techniques of comparative analysis and theoretical sampling were employed. Transcripts were coded for themes which were clustered to form named categories. Grounded theory approach to data collection and analysis proved to be appropriate for the research problem as little has been written about the psychological stress for the patient that follows transplant procedures. Although the limited research carried out is of interest and provide many clinical examples they typically focus on the end result of a patient's adjustment to a stressful situation. Unfortunately they ignore the details or processes of the stress and coping strategies of the heart transplant patients.

The data produced four categories which conceptualised heart transplants recipients' experience:

1) Traumatic experience, 2) Somebody else's heart in side me, 3) Coping, 4) That's a small price to pay for being alive Vs Too big a price

Finally, the categories were arranged around the central theme of the research, *heart transplant recipients' experience* , to form an analytical version of the story.

The theory of "Price to pay for being alive: Coping with the postoperative demands in Heart Transplantation" developed in this study, explains the coping process involved in heart transplant recipients adjustment to the postoperative life. Making the coping process explicit may contribute to an understanding of the problems involved in heart transplantation. Increased understanding of this process could provide indicators for the appropriate care of heart transplant recipients and a theoretical foundation for the education of care professionals. Care professionals, in turn, can assist patients to modify their beliefs about heart transplantation and develop attitudes and beliefs to meet the challenge of living with continual unpredictability.

Dedication

To those who taught me not to be ashamed of my mistakes!

Declaration

I hereby declare that this thesis is of my own composition, and that all assistance has been duly acknowledged. The results presented herein have not previously been submitted for any other degree or qualification.

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CHAPTER 1: Literature review

1.1. Introduction

The purpose of this chapter is to establish a conceptual frame of reference for the study in relation to the central element of its focus the "heart transplant recipients' experience".

The review which follows centres on the literature that is relevant to the present study. The review starts with how coping and coping with stress has been defined and described in the literature. The review continues with how people cope with the problems in a health crisis. Finally it focus on the central themes of this study, namely the coping with the stress following a heart transplantation and the psychological adjustment to the postoperative period. Details are also given of the factors that affect the coping process and the interventions to enhance coping.

1.2. Coping with stress

Coping is commonly defined in the literature as a process of adaptation to perceived threat. Thus, Monat and Lazarus (1991) describe coping as "an individual's efforts to master demands (conditions of harm, threat, or challenge) that are appraised (or perceived) as exceeding or taxing his or her resources" (p.5). Coping processes are typically classified as having either rational or emotional

connotations, but within this broad classification a variety of different strategies have been identified (Roger, Jarvis & Najarian, 1993).

Essentially there have been three different approaches to the study of stress (Cox, 1978,1990; Cox and Mackay, 1981): the stimulus-based or engineering approach; the response-based or medico-physiological approach; and a more psychological approach exemplified by "interactional" and "appraisal" theories of stress. The last named approach owe much to the work of Lazarus (1966, 1976).

The engineering approach treats stress as a stimulus characteristic of the person's environment, usually cast in terms of the load or level of demand placed on the person or some aversive or noxious element of the environment. Stress, so defined, produces a strain reaction. In contrast, the medico-physiological approach considers stress as a "generalized and non-specific" response to aversive or noxious environmental stimuli. This approach owes much to the pioneering work of Hans Selye (1950). Stressors give rise, among other things, to a stress response. Despite a certain popularity, these approaches have been judged to be inadequate both in terms of their ability to account for the available data and in terms of their theoretical sophistication that does not reflect current thinking in psychology. Essentially, they fail to take account of the individual differences which are so obvious in relation to stress, and the perceptual cognitive processes which underpin such differences.

Historically, work on coping processes has been shaped by psychoanalytic conceptions (Freud 1946, Haan 1977), which viewed coping and defense as largely unconscious responses to internal conflicts. Current conceptualizations of coping have also been shaped by social learning theorists (Bandura, 1977; Mischel, 1977), who have emphasized the process of reciprocal interaction between the person and

the environment, as well as by cognitive behaviour therapists (Meichenbaum, 1977), who have stressed the role that cognitive processes play in therapeutic change. All of these formulations emphasise the active role that the individual plays in construing his or her psychological world and in utilizing resources to manage stress or to modify problematic aspects of the environment.

As investigators became increasingly interested in the impact of life events, attention has shifted to the process of coping with external stressors. This shift in emphasis has been largely influenced by the work of Lazarus (Lazarus & Launier 1978), who focused on the role of cognitive appraisal in shaping responses to stress and guiding coping efforts. In the conceptual analysis of stress and coping offered by Lazarus in 1966 (Lazarus and Folkman, 1984), Lazarus argued that Stress consists of three processes. *Primary appraisal* is the process of perceiving a threat to oneself. *Secondary appraisal* is the process of bringing to mind a potential response to the threat. *Coping* is the process of executing that response. According to the Stress and Coping Theory developed by Lazarus and his colleagues over a number of years (Coyne & Lazarus, 1980; Lazarus, 1966, 1981; Lazarus & DeLongis, 1983; Lazarus & Folkman,1980, 1984), Coping is defined as the person's constantly changing cognitive and behavioural efforts to manage specific external and /or internal demands that are appraised as taxing or exceeding the person's resources (Lazarus, 1991). According to Lazarus theory, coping is process oriented, meaning that it focuses on what the person actually thinks and does in a specific stressful encounter, and how this changes as the encounter unfolds. Although these processes are most easily described as a linear sequence, Lazarus has emphasized that they do not occur in an unbroken stream. Rather, an outcome of the process may reinvoke a preceding process. For instance, realizing that an adequate coping response is readily available may cause one to reappraise a threat as less threatening or if the coping response is

less effective than expected, one may reappraise the level of threat or reappraise what coping response is appropriate. By virtue of functioning as moderators, coping processes influence the kind and intensity of stress perception and adaptational outcomes (Lazarus, 1991).

Also according to Folkman and Lazarus (1986), one can not make a priori assumptions about what constitutes good or bad coping; coping is defined simply as a person's efforts to manage demands, whether or not the efforts are successful. This feature contrasts with animal models in which coping is defined as instrumental acts that control an aversive environment and, therefore reduce arousal (Ursin, 1980). It also contrasts with traditional ego-psychology conceptualizations that consider certain strategies inherently less desirable than others (Menninger, 1963), or that label a strategy as "coping" as opposed to defense only if it satisfies certain criteria such as adhering to reality (Haan, 1977).

The main appeal of Lazarus model, according to Bailey and Clark (1989), is the way in which can be applied to real life, and it can provide a framework for coping strategies which may help individuals, especially in the face of unavoidable threat or demand. This latter property is its advantage over previous formulations of stress models which leave the individual responding rather passively or even helpless in the face of threat. Within this model, the perceived source of threat can be identified, and coping strategies can be planned. The relationship between threat and coping can be made explicit and the individual may be helped to gain personal control over threat or demands imposed by the physical and social environment. An individual who understands the model gains the knowledge to analyze the situations they judge threatening; to gain insight into characteristics of threatening situations; and also to develop a range of coping strategies. Finally, it allows one continually to evaluate the

efficacy of the coping strategies he/she uses. Theoretically the model can account for individual variation in stress and coping, unlike the stress as stimulus and stress as response model.

According to Abraham and Shanley (1992), in Lazarus model the individual is not seen as a passive victim of environmental demand. He/she is portrayed as an active agent whose interpretation of situations determines how he/she experiences them. This has the crucial consequences of highlighting the individual's power to reduce or avoid stressful experiences. The perceived threat is the person's own creation in that it is derived from his/her representation of reality. It may be based on memories of past experiences, present circumstances or anticipated events and can be experienced even when the stressor is not present. The model also acknowledges that the same threat may elicit different responses at different times from the same individual. The person's experience depends upon his/her appraisal of demands and the coping resources at a particular moment. This suggests that helping others to cope with stressful situations begins with focusing on the "here and now", that is, what the person is feeling at that moment. In same cases people perceive what to others is harmless as very threatening. Extreme examples are seen in phobias where specific objects (such as animals) are experienced as threatening and sometimes terrifying. Coping with these threatening situations depends upon the person's ability to change his / her appraisal or interpretation from a threatening to a non-threatening one (Abraham & Shanley, 1992).

Bailey and Clarke (1989) also argued that, the transactional model of Lazarus (1966), as like other formulations of coping does have a number of limitations. First, it is a very general approach to the way people cope and as such is better for analysis than prediction. A second criticism, however, is that the approach does not allow

prediction of individual behaviour. That is, who will cope in what way and to what effect.

Although there are many ways to classify coping responses (Moos & Billings, 1982), most approaches distinguish between strategies that are active in nature and oriented toward confronting the problem, and strategies that entail an effort to reduce tension by avoiding dealing with the problem. Lazarus and Folkman (1984) proposed a typology of coping processes that distinguishes between problem-focused strategies (efforts to modify the source of stress) and emotion-focused ones (attempts to regulate the emotional distress caused by the stressor). Although emotion-focused strategies can be active, such as constructive efforts to regulate affective responses to a stressor, such coping is often oriented toward avoiding dealing with the source of stress (Holahan & Moos, 1987).

Cognitive models, however, have been criticized for their high levels of generality, and a lack of focus upon the strategies and resources which encourage better or poorer adjustment (Stroebe & Stroebe, 1987). While generally accepting the usefulness of problem- and emotion-focused coping in particular, critics argue that more understanding is needed of interpersonal resources, especially the personality traits and the interpersonal resources that assist coping, such as social support (Gallan & Hennessey, 1989).

Pearlin and Schooler (1978) also differentiated between efforts to change the situation and attempts to control distress, as well as responses that alter the cognitive appraisal of the stress. Billings and Moos (1981) suggested a related typology consisting of active-behavioural strategies (overt behavioural attempts to deal directly with the problem), active-cognitive strategies (efforts to manage the

appraisal of the stressfulness of the event), and avoidance strategies (attempts to avoid confronting the problem or to indirectly reduce tension by behaviours such as eating or smoking more). According to Rohde, Tilson, Lewinsohn, & Seeley (1990), in addition to the role of coping as a mediator of stress, the dimensionality and specific nature of coping clearly deserve attention. Clarifying the dimensionality of coping is important in developing a better understanding of what people do under stressful conditions. Such understanding would be useful in developing clinical interventions for use by individuals in stressful situations.

Basic to cognitive models of coping (Lazarus & Folkman, 1984; Moos & Schaefer, 1986) are assumptions that coping skills can be taught and that individuals can master situations perceived to be stressful.

As Kahn, Steeves & Benoliel (1994) state, coping is an important subject in most of the clinical arenas in which nurses practice. Every day in such settings nurses attend to, assess and evaluate the coping of their patients, talk about this coping among themselves and with other practitioners, and comment upon and document evidence of coping in clinical records.

According to Bailey and Clarke (1989), a thorough understanding of the concept of coping can help a nurse in her day-to-day work. First it can important to the health education, by teaching the patient to cope; and for those patients who have developed their own coping strategies, a knowledgeable nurse can give reinforcement and support. Learning to cope not only gives nurses control over their own lives and well-being but leaves them free to concentrate on helping patients.

Historically, the term coping is a relatively recent development in the language of nursing practice. For example, coping was first indexed in the *Cumulative Index to Nursing and Allied Health Literature* in 1979, encompassing material formerly indexed under the terms, defense mechanisms and, especially, psychological adaptation. Presumably, the increasing emphasis on patient's coping in the nursing literature has been related directly to the changes in the philosophy of and the recognition of stress as a pathogenic factor. This stress paradigm, set forth in the classic text by Lazarus, defines coping as a response to stressors in terms of both problem solving and emotion regulating behaviours (Lazarus, 1966). Nursing researchers have found the paradigm useful in examining stress related issues (Kahn, et.al., 1994).

1.3. Coping With Health Crisis

According to Moos (1984) the crisis of acute physical illness is an unusually potent stressor that may extend over a long period of time and lead to permanent changes among patients and their family members. The potency of the crisis stems from the typically sudden and unexpected onset and the pervasive threat to the essence of an individual's life and adaptation. A person may face hospitalization and separation from family and friends, overwhelming feelings of pain and helplessness, permanent changes in appearance or in bodily function, the loss of key roles, and an uncertain unpredictable future involving the prospect of an untimely death. Such changes involve unique adaptive tasks and the need to use new coping skills

Moos' (1977) Crisis Theory is concerned with how people cope with major life crises and transitions. Crisis theory has provided a conceptual framework for

preventive mental health care and for the handling of severe physical illness or injury. The fundamental ideas were developed by Lindemann (1944), who described the process of grief and mourning and the role community caretakers could play in helping bereaved family members cope with the loss of their loved ones. Combined with Erikson's (1963) formulation of "developmental crises" at transition points in the life cycle, these ideas paved the way for Caplan's (1964) formulation of crisis theory. Moos (1984) presented a conceptual framework of physical illness as a life crisis describing how patients and staff cope with the stress of illness and of treatment.

An acute episode of a serious physical illness or injury, as stated by Moos (1982), can be understood as a life crisis or transition; a cognitive appraisal of its significance leads to the formulation of basic adaptive tasks to which various coping skills can be applied. The individual's cognitive appraisal, definition of the adaptive tasks involved, and selection and effectiveness of relevant coping skills are influenced by three sets of factors: sociodemographic and personal characteristics, aspects of the illness such as its timing and stage, and features of the physical and sociocultural environment. These factors together affect the resolution of the initial phase of the crisis. The result of this coping process with the disease is therefore seen as an interaction between the adaptive tasks and the coping capabilities (Moos, 1977).

As Haan (1979) points out, the problems that involve in a health crises are compounded by specific features of health crises that make it difficult for an individual to select appropriate coping strategies to assimilate and accommodate to the sudden turn of events. For instance, health crises usually cannot be anticipated, their meaning for the individual is ambiguous, clear information is lacking, and it is often necessary to make definitive decisions quickly. A high potential for

maladaptive coping is created by the sudden life-threatening anxiety particularly if little or nothing can be done to change the illness itself. Family members, who also may be uncertain about what to do, may react in ways that encourage maladaptive responses on the part of the illness-stricken individual. In addition a person may have only limited prior experience in handling serious illness and thus cannot rely on previously successful coping responses.

Patients often regard their disease as the source of major discontinuity in their lives and report permanent changes in their adaptation, self-concept, and perception of the future (Croog and Levine 1977; Mages and Mendelsohn 1979). On the other hand, other patients do cope adequately with the aftermath of an illness. Long-term survivors of serious illness can attain levels of psychological and social functioning that are similar to those of their "normal" counterparts in the community (Craig, Comstock, & Geiser, 1974). Furthermore, some people report enhanced personal growth and integration after experiencing an illness (White & Liddon, 1972). In a study of survivors of serious illness, Smith (1979) noted greater concern for and sense of community with others, a change in focus of energy from the constant pressure of work to family relationships, more realism and acceptance of life, and heightened awareness of religious and humanitarian values.

In the framework of the psychological stress paradigm, a psychological crisis caused by the illness can be interpreted as a stressful situation. The stressful conditions usually elicit in the individual attempts to overcome or master them (Egger & Stix, 1984). According to Lazarus, Averill & Opton (1974), these attempts contain all types of behaviour which may help an individual to avoid or minimize a state which is considered as unpleasant and is caused by the disease. The trigger for stress reactions is dependent on the concept of the individual's appraisal of the threat.

Through the illness, depending on the personality of the patient, the fulfillment of important needs or motives can be considered to be threatened, like autonomy and control over the accustomed way of life up until the illness. When this person experiences a diminishing of fulfillment of these important needs or motives, or imagines this process in his thoughts, he begins to look for possibilities of removing the fear, without at the same time suffering from new anxieties for subjective important motives. The type and progression of this coping with fear again depends on many factors, such as the nature of the situation, personality factor and social-environmental factors (Lazarus, & Cohen, 1977; Hamburg, Coehlo & Adams, 1974; Adams & Lindemann, 1974).

According to Fife (1985), implications of medical crises for the quality of patient's life necessitate the development of strategies that will facilitate identification of those patients at high risk of failure to cope adequately. However, little has been done to identify factors associated with poor adaptation of patients to medical crises.

Few life crisis studies tried to explore the relationship between coping processes and adjustment. The vast majority of studies of coping with specific life crises have focused on the process of coping with physical health problems or with major surgery (Lazarus & Cohen, 1977). In almost all cases, the studies have focused on the impact of denial on recovery (Cohen & Lazarus, 1979; Mullen & Suls 1982) and have utilized outcome measures indicative of physical health status.

The conventional method of describing the subjective reality of a chronic organic disease generally includes patient case histories (including questionnaires regarding the past life and psychosomatic inquiries), a symptom profile (type and severity of the organic and psychic complaints, tests of the actual situation) and

psychodiagnostic tests (personality tests). An illness-specific understanding of the emotional-cognitive pattern of reaction to an organic disease is often absent. Therefore data are missing which give information regarding the appearance of the crisis due to an illness, with its emotional, cognitive and behavioural attempts to overcome it (Egger and Stix, 1984). Egger and Stix (1984), developed a survey within the framework of a psychosomatic research project on the coping process with illness in patients with cardiovascular or cerebrovascular disease. The survey gives particularly detailed information concerning the patient's cognition (thoughts, opinion, evaluations, considerations, assessments, plans and expectations) and emotions (feelings, affective changes, moods), when patient is confronted with such an illness. The survey gives a relevant overview and useful insight in the patient's reality, his/her adapting, and coping reactions, the meaning of the chronic disease for his/her self-conception and way of life, as well as possibilities or necessities for psychological interventions and other treatment aspects.

Only few studies have examined the role of coping strategies in facilitating adjustment to such life crises as loss of a child (Videka-Sherman, 1982); rape (Burgess & Holmstrom, 1979); permanent paralysis (Rosenthal & Roth 1981); divorce (Berman & Turk, 1981). For the most part, these studies are characterized by methodological shortcomings such as small and underpresentative samples. Moreover, almost none of these studies have included adequate measures of psychopathology. Taken together, however, these studies provide suggestive evidence that coping processes may play a role in ameliorating the impact of life stressors.

A factor according to Kessler and Wortman (1985), that life crisis researchers have tended to ignore, is that there are likely to be important differences between

respondents in the amount and type of stress that is experienced from particular crisis. The authors suggest, that more work is necessary to describe various objective features of life crises so that the impact of coping strategies and other variables such as social support can be assessed more adequately. Also, another issue that has received relatively little attention among life crisis researchers concerns the appropriate focus for questions about coping. In studies on bereavement, for example, a concern is whether individuals should be asked to identify those strategies that they are using to cope with the experience of loss in general, or they should be asked to indicate how they are coping with the variety of problems that accompany the loss, such loneliness, financial matters, or households. Most investigators have restricted their focus of inquiry to coping with the crisis as a whole. If the life crises have their impact through the chronic strains that accompany them, it may be useful to assess coping with these associated stressors.

In summing, more research is needed to explore the relationship between coping processes and adjustment and to provide evidence that coping process may play a role in ameliorating the impact of stressors in a health crisis. A better understanding of the adaptive tasks and coping skills involved to a health crisis may assist the health professionals to provide appropriate interventions that support healthy coping and minimize the negative impact of the illness experience.

1.4. Coping with Heart Transplantation

1.4.1. Introduction

In the past decade, heart transplantation has become a viable treatment option for patients with end-stage heart disease. Recipients are selected from among patients with end-stage ventricular failure-namely those who are identified as clinically with New York Heart Association (NYHA) class III or IV- who are unlikely to survive more than one year and for whom there is no alternative therapy (Kaye,1993).

The number of patients waiting for and receiving hearts has grown exponentially. Before 1980, fewer than 360 heart transplantations were performed (Kriett & Kaye, 1991), but just 13 years later (December 1993) 26,704 heart transplantations had been performed worldwide (Hosenpud, Novick, Breen, Keck, & Daily, 1995). The International Heart Transplant Registry reports that while survival was measured in days or months in the early stages of heart transplantation 20-25 years ago, current survival rates for one year are 85-90%; survival rates for five years are 73% and the ten years survival rate is 50%. Most cardiac transplant recipients are male (81%) and white (86%). Ages range from new-born to 72 years, with a mean age of 44 years (Hunt, 1993; Kaye, 1993).

The current level of success in cardiac transplantation is attributed to advances in immunosuppressive drugs, antimicrobial agents, methods to detect rejection, and organ procurement and organ preservation (Muirhead 1992). Multidisciplinary research continues to study the problems in cardiac transplantation. Current efforts to address some of the difficulties include attempts to increase the availability of donors, the search for alternatives to transplantation, the discovery of better

immunosuppressive techniques, the prevention of long-term complications and the promotion of effective psychosocial rehabilitation (Dressler 1993).

A heart transplantation is not an event but a process that continues for the rest of the recipient's (and his or her family's) life (Larsson & Molle, 1994). Although cardiac surgeons often emphasize the surgical procedure, it is what precedes and follows the surgery that receives the enduring attention of the recipient and others involved. The heart transplantation introduces the recipient to a new set of problems to replace the old ones (Larsson & Molle, 1994).

Patients who proceed through the process of transplantation are taken through a long series of events that begins with the proposal of the procedure and continues long after the operation. Patients may progress from a terminal state of heart failure to an active lifestyle. This process is accompanied by physical and psychological perils that require ongoing assessment and intervention by physicians and nurses experienced in transplantation (Dressler 1993). Survival has for many years been the only one goal of cardiac replacement. However increasingly the quality of survival is seen as important and is defined not only by recipients' cardiac function and general health, but their long-term psychological adaptation during the post-transplant years (Dew, 1993).

With the improved survival rate following heart transplantation, evaluating some of the psychosocial outcomes has become a major focus of medical and nursing research. The heart transplantation process has been conceptualised as a series of stressful stages. These involve recognition of life-threatening illness and decision for transplantation, waiting for a donor, and recovery from transplant surgery. These stages and how people cope and respond during these phases have been described

(Alleder, Shisslak, Kaszniak, & Kopeland, 1983 ; Christopherson, 1987; Kuhn, et. al., 1988).

Despite the increase in interest in quality of life issues, the medical literature is scant in regard to the psychosocial impact of cardiac transplantation on recipients, and a systematic and prospective study of the psychosocial adaptation of recipients is lacking. Most of the research on psychological aspects of heart transplantation (Mai et al., 1986; Surman, 1989; Shapiro et. al., 1989; Nussbaum & Goldstein, 1992), are based on quantitative methodologies, using health questionnaires and symptoms checklists and relatively small samples. The existing literature on psychosocial outcome for heart transplant recipients presents conflicting findings, and these findings are based on small samples and the use of self-report questionnaires without other validation. An exception is a study by Shapiro and Kornfeld (1989), who evaluated 73 heart transplant recipients, with semi-structured diagnostic interviews, 1 month to 6 years after transplantation to determine the prevalence of psychiatric disorders and psychosocial problems after heart transplantation. Findings of this study suggested that, patients' prominent psychosocial problems include affective illnesses partly related to steroid drugs; sexual problems associated with cyclosporine-induced hypertension; adjustment problems associated with other side effects of steroids and cyclosporine and with convalescence from life-threatening illness; family and marital difficulties, and social problems related to employment, insurance, and finances.

Most of the research (Evans et al, 1984; Lough et al, 1985; McAleer et al, 1985; Wallwork & Caine, 1985; Mishel & Murdaugh, 1987; Kraft, 1971; Molish et al., 1971; Cristopherson et al., 1976) that has been done in the area of heart transplantation typically focus on the end result of a patient's adjustment to a

stressful situation while ignoring the details or processes of the stress and coping strategies of the heart transplant patients. In order to have a better understanding of the reactions and adjustment of heart transplant recipients, a more systematic study of the difficulties they face, and the way they experience and cope with them, is needed.

1.4.2. Stress following heart transplantation.

According to Leedham and colleagues (1995), successful heart transplant recipients may develop a complex lifelong regimen of new habits, including daily monitoring for changes in blood pressure and indications of infection, periodic biopsy to detect possible rejection of the donor organ, appropriate exercise and diet, and adherence to elaborate medication schedules. In addition to these adherence challenges, transplant recipients find themselves in an unusual psychological predicament. The postoperative phase of heart transplantation requires adequate coping strategies if successful adaptation is to be achieved (Dressler, 1993). Patients may be euphoric immediately after operation but, as setbacks and complications occur, may realize that they are still vulnerable to problems. The recipient has to live with the uncertainty of the rejection of the transplant or infection and to cope with the side effects of medication. In addition to medical problems, transplant patients may experience difficulties with body image, role changes, family and marital stress, employment, finances, and emotions (Dressler, 1993).

As Dew et al (1994) state, although the act of organ transplantation itself is an acute stressor, its long-term aftermath, like many other major life events, more closely resembles a situation of chronic stress. The situation is composed of a

constellation of interrelated elements, the chief of which is the continuing uncertainty regarding its clinical course that arises from unpredictable occurrences of infection, graft rejection, and secondary illness. Additional stressful features include changes in physical appearance induced by immunosuppressive medications, and other pharmacological side effects. With respect to heart transplantation in particular-in notable contrast to kidney transplantation-heart recipients are aware that their lives can rarely be maintained successfully for long periods by cardiac equivalents of hemodialysis (as left ventricular assist devices) in the event of graft failure.

As Bunzel et al (1992) state, heart transplantation therefore is unique among all operations and cannot be compared to other transplantations. It involves a confrontation with symbolic and mythological concepts that are hard to fathom. Heart transplantation obviously is not simply a question of replacing an organ that no longer functions. Kuhn et al (1988) summed up their results concluded that apparently no other procedure in medicine or surgery confronts the patients with comparable emotional stress.

Research on other domains of life stressors and illness (Dohrenwend & Dohrenwend, 1981; Kessler et.al., 1985; Coyne & Downey, 1991) suggests that the psychosocial stress emanating from the post-transplant period may have uniquely deleterious mental-health consequences. Three strands of transplant-related research support this concern. First a small but growing literature indicates that psychological distress occur during the post-operative recovery period following heart transplantation (Mai et.al., 1986; Frierson & Lippman, 1987; Freeman et al., 1988; Dew et.al., 1991; Riether et al., 1992). Some reports, however, suggest that stress effects may persist well beyond the perioperative period. Extended stress effects have been noted to occur primarily in the areas of depressive and anxiety-related

difficulties (McAleer et al., 1985; Shapiro & Kornfeld, 1989; Mai et al., 1990; Maricle et al., 1991; Phipps, 1991). The likelihood of observing distress in these areas is heightened among patients with a history of pre-transplant psychological problems (Freeman et.al., 1988; Kuhn et al., 1988; Mai et. al., 1990; Phipps, 1991).

These earlier findings, however, were based on generally small samples of fewer than 30 persons, and/or on samples referred for psychiatric evaluation during the first year post-transplant. Thus, these findings may be limited in the extent in which they can be generalized. In addition, these studies typically relied on single cross-sectional assessments of psychological status post-transplant, thus preempting their ability to examine changing distress patterns as the transplant experience itself recedes into the past. For example Mai's (1990) study about the psychological adjustment and quality of life following heart transplantation appeared to have some shortcomings. Perhaps the most important is the lack of validity and the limited reliability for the Physical Activity and the Work and Employment Scales. Ideally they would need to be validated using a larger (than 27 as is in this study) number of physically ill patients, and comparing the rating scores with global clinical ratings carried out separately; as normative reliability studies were not carried out for the present study. A further difficulty of the study was that the PAS and WES ratings were carried out retrospectively and they were based on the written case record of the pre- and post-operative medical, psychiatric and social work examinations. Similarly, the post-operative sexual activity rating was based on the psychiatric and social work case record.

The second strand of evidence comes from two larger-scale longitudinal studies of representative samples of heart recipients which found that, while post-transplant distress levels generally decline over time, a substantial proportion of heart recipients

may continue to experience impaired psychological functioning even one or more years post-surgery (Wallwork & Caine, 1985; Evans, 1987; Caine & O'Brien, 1989). Unfortunately, these investigations were designed as general analyses of a broad range of quality of life issues, and focused primarily on overall perceptions of emotional well-being. Thus they did not include in-depth assessments of psychological symptoms post-transplant, or risk factors for such symptoms.

Finally, sociological analysis of organ recipients' long term reactions and adaptation yields a third line of suggesting evidence regarding long-term mental health effects (Simmons & Anderson, 1982; Simmons et.al., 1987,1988). Although the previous studies also investigated more general quality of life issues rather than psychological status per se, they, too, observed that large proportions of their sample experienced continually elevated depressive affect and anxiety levels, even at one-year post-surgery.

It is therefore important to identify a broad range of psychological factors that influence the recipients' ability to adapt to the stressors that emerge following transplantation. As Zumbrunnen (1989) suggested, psychological adjustment with these stressors requires effective coping abilities.

1.4.3. Coping and psychosocial adjustment to post- heart transplant period.

As Mai et al (1990) reported, few studies however have examined the psychosocial adjustment and quality of life in heart transplant recipients. According to Duitsman (1993), further exploration of psychological factors and their contribution to quality of life is important to the overall improvement of the heart

transplant patient's quality of life. So far, the difficulty of finding adequate control groups, and problems in carrying out prospective studies have led to a paucity of information about the psychological functioning of patients following heart transplantation and its determinants (Strauss et al., 1992). Another approach that does not depend on meeting these requirements such as a qualitative approach may be a more appropriate method in identifying psychological factors and their contribution of quality of life.

The patient's ability to cope with the stressors that come after the transplantation is an important factor in achieving the highest possible level of quality of life (QOL), and is likely to affect the degree of prolongation of life itself (Christopherson, 1987; O'Brien, 1985; Shapiro, 1990; Suszycki, 1988). The quality of life after heart transplantation has been studied by Christopherson (1987), who found that although quality of life (in terms of return to work or school) was enhanced, patients continued to be concerned about limited life expectancy. In addition, using a multidimensional approach with two instruments, the McMaster Health Questionnaire (Chambers, 1984) and the Cantril Self-Anchoring Scale (Cantril, 1965), Packa (1989) observed a higher quality of life, mostly in physical function but also in social and emotional function, after the heart transplantation. However, other studies indicate that quality of life remains at a low level after a heart transplantation, especially in terms of the family's function (Mishel, & Murdaugh,1987). All of these studies are based on quantitative methodologies measuring only few of the aspects that can be included in quality of life measurement (Caine, Sharples, English, Wallwork, 1990; Bohachick, Anton, Wooldridge, 1992). Few studies have examined quality of life longitudinally from before to after transplantation (Wallwork & Caine, 1985; Mai, McKenzie and Kostuk, 1990; Bunzel, Grundbock, Laczkovics,

Holzinger, Teufelsbauer, 1991; Jones, Taylor, Downs, Spratt, 1992; Caine, Sharples, English, Wallwork, 1990); but all of these studies were retrospective.

One of the largest (n=148) studies of quality of life in patients undergoing heart transplant, was the one by Grady, Jalowiec, and White-Williams (1996); the purpose of this study was to compare quality of life of patients at the time of listing for a heart transplant with 1 year after the operation. Major dimensions of quality of life measured in this study were as follows: health (symptoms and health perception), physical and emotional functioning (functional status), and psychosocial functioning (stress, coping, life satisfaction, and overall quality of life). The conclusions of this study were that end-stage heart failure patients had improved quality of life from before the operation to 1 year after heart transplant due to less total symptom distress, better health perception, better overall functional status, more overall satisfaction with life, and improved overall quality of life; post-transplant patients still experienced some symptom distress, functional disability, and stress, but were coping well. Several shortcomings make the findings of questionable use.

First conclusions that the patients had improved overall quality of life are inconsistent with the results, where no significant differences were found in total stress, coping use, and coping effectiveness from before the operation to 1 year after heart transplantation. The authors did not relate results of measures of stress, coping, and coping effectiveness to the overall quality of life. Secondly, findings that patients still experienced some stress but they were coping well were inconsistent with the results, where no significant differences were found in total stress, coping and coping effectiveness. Third, the claim for the study being a longitudinal investigation is inappropriate as the comparison was made at only one time before versus after transplantation. A longitudinal study of quality of life need to include

comparison of multiple time periods both before and after transplantation and at regular intervals following discharge from the hospital (Wenger, Mattson, Furger, & Elinson, 1984). Therefore the claim that the study constituted a longitudinal study is questionable.

Larsson and Moller (1994) found that, pre-transplant problems may have an impact on the recipient's post-transplant quality of life (QOL). His or her coping capacity, coping strategies, and level of adaptive compliance during the pre surgical waiting period may serve as predictors for post transplant QOL. Larson et al (1994) conducted a collaborative study between centres in Sweden, Denmark and United States, to assess quality of life in relation to heart transplantation. The study was longitudinal and patients completed the instrument "Coronary Health Profile" at different stages: during the evaluation period; after acceptance but before the transplantation; four to five weeks after transplantation; one and three years after transplantation. During the evaluation period there was a complementary interview about the coping strategies that the patients used earlier in life, their expectations of life after heart transplantation and their experienced capacity to cope with both the present and forthcoming situations.

These interviews, conducted and analyzed according to the grounded theory method (Glaser & Strauss, 1967), deal with the patient's coping strategies in relation to events that are experienced as stressful and with prior and present levels of compliance with medical regimens. The preliminary results of this ongoing study indicated a clear relationship between coping capacity and studied psychological factors. Low levels of coping capacity were related to high levels of experienced depression, loneliness, anxiety, and stress, while high levels of coping capacity were

related to low levels or the absence of experienced depression, loneliness, anxiety, and stress.

This was the first study found to measure coping strategies using a qualitative approach and grounded theory. It could have been of great value if the interviews could have been conducted in all the different stages, including the postoperative period; and also if coping strategies were related to events that were experienced as stressful other than only the compliance with medical regimens.

Various approaches to making sense of coping processes are present in the literature (Christopherson 1987; Zumbrunnen, 1989; Allender, et al., 1983; Jones 1988). According to Christopherson (1987), the coping mechanisms used by cardiac transplant patients often reflect the stages described by Kubler-Ross (1969): denial, anger, bargaining, depression. Authors of psychoanalytical orientation (Baudin, 1989; Castelnuovo-Tedesco 1978; Kraft 1971) refer to the defense mechanisms terminology and point-out : denial, regression, rationalization, among the defensive mechanisms used by transplant patients. Some authors describe psychological "responses" to transplantation (Jones 1988) which seem to include both the coping mechanism and its outcome (feelings of anxiety, depression, frustration etc.). Finally, most researchers have not used definite categorization but describe concretely the patient's behaviour according to the phase he/she is facing (Freeman 1984; Kuhn, et al 1988; Gutkind 1988).

For the patient, heart transplantation means more than an operation. Patients have to cope with a dual challenge: the loss of their own heart and the acceptance of a donor heart (Rogers, 1984). Psychologically, losing one's heart and having it replaced by somebody else's, an anonymous donor who was the target of disease or

accident or even suicide, can mean a threat to one's self-concept (Bunzel, et.al., 1992). Several studies, most of which describe the practical experience with patients, deal with the problem of how patients cope with that strain. Rauch and Kneen (1989) described the patient's feelings of guilt about the donor's death. They wrote that emotional turmoil and perceived threats to the integrity of the self interfere with psychological integration of the new heart. They agree that psychological rejection of the heart is sometimes associated with physiological rejection. Meserve (1984) and Norvell et al (1987) found that the mythological qualities ascribed to the heart by a person complicate the recipients' acceptance of the organ. Both Castelnuovo-Tedesco (1978) and Kraft (1971), stated that the newly transplanted heart is not psychologically inert, threatening the continuity, stability, and nature of the self. In the worst cases, psychosis and major psychiatric symptoms may develop. Rodgers (1984) even stated that a "psychological transplant" exists in addition to the organic, because patients often feel forced to accept some characteristics from the deceased donor.

While a large body of research indicates that survivors of heart transplantation achieve a quality of life superior to their pro-transplant status (Brennan, Davis, Buchholz, Kuhn, & Gray, 1987; Caine, Sharples, English, & Wallwork, 1990; Hunt, 1985; Jones et al, 1988; Meister, McAleer, Meister, Riley, & Copeland, 1986), there appear to be a substantial number of patients who do not achieve optimum recovery outcomes (Lough, Lindsey, Shinn, and Scotts, 1985). Samuelsson, Hunt, & Schroeder, (1984); McAleer, Copelant, Fuller, and Copeland, (1985) patients reported that they were not really satisfied with their life since transplantation. In a study by Bohachick, Anton, Wooldridge, Kormos, Armitage, Hardesty and Griffith (1992), to evaluate the effect of heart transplantation on psychosocial functioning by comparing pro-transplant functioning against 6 months after post-transplant, findings

support the research that indicates that most survivors of heart transplant achieve a quality of life superior to their pro-transplant status. The great majority of patients demonstrated significant improvement in psychosocial adjustment and emotional states. However, given that one-quarter of the patients showed a negative change in their psychosocial adjustment following heart transplantation, further study is indicated to identify factors important to post-transplant psychosocial adaptation.

Zumbrunnen (1989) asserts that there is no study devoted to the systematic assessment of coping mechanisms used by cardiac transplant patients, although the literature on psychological adjustment to cardiac transplantation is abundant (Christopherson 1987; Allender 1983; Jones 1988).

However, it is difficult to assess coping and coping effectiveness, using only self-report instruments. The difficulty concerns the extent to which patients are aware of their coping strategies, and whether patients can accurately report the coping strategies they use. The assumption that respondents are capable of reporting their coping efforts has been criticized (Horowitz & Wilner, 1980; Haan, 1982; Ray, Lindop, and Gibson, 1982). These investigators believe that coping efforts are not always deliberate or conscious and the indirect assessments of coping are therefore necessary. Few attempts have been made, however, to compare self-reports about coping with more indirect projective assessments or with clinical observations (Haan, 1982; Stone & Neale, 1982). Therefore, there is little empirical evidence with which to adjudicate between these contending positions.

1.4.4. Factors Affecting the Coping Process

The coping ability of a patient is influenced by several factors, including: personality, specific significance of the illness phase, as the severity level of physical illness, previous illness experiences, and available external support (Zumbrunnen 1989; Kuhn 1988).

1.4.4.1. Personality characteristics

The personality characteristics and the individuals differences in coping were discussed broadly in the literature:

Kobasa (1979) and Wheaton (1983) focused on characteristics of the personality that are antecedents of coping. Wheaton (1983) considered fatalism and inflexibility, and Kobasa (1979) considered hardiness. Hardiness, is a composite of three dimensions (commitment, control, and challenge) that reflect the existentialist approach to personality (Kobasa 1979). Hardy individuals presumably are active copers, making the best of situations they are in and unlikely to engage in denial or disengagement. The assumption underlying this approach is that personality characteristics dispose the person to cope with certain ways that either impair or facilitate the various components of adaptational status. However, there is little evidence that these personality characteristics do in fact significantly influence actual coping processes (Cohen & Lazarus 1973, Fleishman 1984). A range of personality characteristics including values, commitments, goals and beliefs about oneself and the world helps to define the stakes that the person identifies as having relevance to well-being in specific stressful transactions (Folkman & Lazarus 1986).

According to Carver et al (1989), who studied the role of self-esteem and mastery to coping, self-esteem refers to the positiveness of one's attitude toward oneself. Self-esteem is a crucial personality component contributing to the consistency and stability of social response. High self-esteem is taken as a mechanism which functions to maintain and preserve self-evaluation and self-direction . People high in self-esteem presumably engage in positive, active attempts to cope with stressors (Pearlin and Schooler 1978). People high in self-esteem perhaps have a past history of considerably more successes than failures in mastering environment and in coping with impinging external stresses and threats. Those low in self-esteem tend to become preoccupied with distress emotions, and be more likely to disengage from their goals when under stress. Mastery, concerns the extent to which one regards one's life-changes as being under one's own control in contrast to being fatalistically ruled (Carver 1989).

Pearlin and Schooler (1978) evaluated personality characteristics indicative of the possession of psychological resources (mastery, self-esteem, and self-denigration, that is negative attitudes toward self) and the ways in which people cope with chronic role strains in relation to the ameliorating of distress in each of five role areas: marriage, parenting, household, economics and occupation. The data presented, was gathered through scheduled interviews with a sample of 2300 people representative of the population in the Census-defined urbanized area of Chicago. Findings of this study, suggested that psychological resources embodied in self-attitudes can help blunt the emotional impact of persistent problems. There is, also, a fairly clear order in the efficacy of people's psychological recourses in vitiating stress: freedom from negative attitudes toward self, the possession of a sense that one is in control of the forces impinging on one, and the presence of favourable attitudes toward one's self.

Cox et.al. (1991) reviewed three particular individual difference variables: hardiness, locus of control and the nature of coping. The first includes the notion of control as one component of essentially a personality construct, while the second focuses on generalized beliefs about control loosely based on reinforcement theory. Albeit at a different conceptual level, coping is itself an individual- difference variable, one possibly influenced, in turn, by other such variables. Differences in coping style are obvious between individuals when attempting to deal with stressful transactions. These differences may well moderate the stress-outcome relationship.

Hardiness has been defined as a personality construct composed of three characteristics: control, which refers to a belief in one's ability to influence events; commitments; which refers to an approach to life marked by curiosity and a sense of meaningfulness; and challenge, which refers to an expectation that change is normal and stimulates development (Kobasa, Maddi, & Courington, 1981). Kobasa variously argue that individual differences in "hardiness" moderate the stress-outcome relationship. She have also suggested that "hardiness" has a mediating effect in relation to primary appraisal (Kobasa, Maddi, & Kahn, 1982).

The notion of locus of control (Rotter 1966) is based on the belief that outcomes (reinforcements) are either due to personal factors (internality) or caused by factors external to the individual (that is, fate, chance or significant others). Several studies have examined the moderating effects of locus of control on the stress-outcome relationship (Johnson et al, 1978).

The appraisal is mediated by individual differences, and the coping which may follow varies between individuals. Coping is, in a sense, an individual-difference variable (Cox and Ferguson 1991). Strickland (1978) noted studies that indicated

that people with an internal locus of control are more likely than people with an external locus of control to engage in an information search about disease and health maintenance when it is relevant to their well-being and in preventive behaviours, such as wearing seats belts and going to the dentists for check-ups. These behaviours are classified as problem focused within the theoretical framework of stress and coping adopted. Furthermore, Anderson (1977) found that, in comparison with externals, internals were likely to employ more task-centred (problem-focused) coping behaviours and fewer emotion centred coping behaviour.

Of interest also is Anderson's (1977) finding that internals whose performance improved become even more internal, whereas externals who gave a poorer performance became more external. These findings suggest that beliefs about control are reinforced by experience, as is assumed by social learning theory (Bandura 1977; Rotter 1966, 1975). The pattern seems to be self-fulfilling: the person who feels challenged generates fewer negative emotions that require attention and is therefore in a position to engage in problem-focused coping efficiently. If the outcome is perceived as positive, it reinforces the appraisal of challenge. The threatened person, on the other hand, experiences much negative emotion, the regulation of which impedes problem- focused coping. The adaptational outcome is poorer, and the basis for feeling threatened is reinforced (Folkman 1984).

In a review of the literature dealing with the relation between locus of control and behaviour related to physical health and illness, Strickland (1978) suggests that internal locus of control improves health because it is associated with preventive behaviour, efforts to improve physical functioning and greater resistance to physical and psychological dysfunction. In the area of mental health, it was found that people with internal locus of control suffered less from severe psychiatric disorders

(Lefcourt 1976) especially from chronic depression (Abramson et al, 1978; Solomon et al, 1989).

Carver et al (1989) choose some specific personality variables to study because each seemed to suggest a conceptual basis for either a preference for active task-engaged coping or a tendency to respond to the stresses of life. They chose the personality dimension of optimism versus pessimism. Because optimists have favourable expectations for their future, optimism is associated with active coping efforts and with making the best of whatever is encountered. Because pessimists have unfavourable expectations for the future, pessimism is associated with focus on emotional distress and with disengagement.

Several theorists have argued cogently for the utility of optimism as a buffer against debilitating anxiety or depression (Lazarus 1983, Taylor and Brown 1988). In contrast, it is also clear that on some occasions and for some individuals, a strategy of defensive pessimism (Norem & Cantor, 1986) can serve effectively to cushion the individual against the debilitating anxiety prior to stress-provoking tasks and to motivate continued persistence in the face of that stress. Defensive pessimists report being more anxious prior to beginning a task, think about and plan for possible "worst case" outcomes, and do not deny control over failure versus success outcomes after the task is completed. Moreover, their performance can be debilitated when they are overtly encouraged (Noren and Cantor 1986, Cantor & Norem, 1987). In contrast, optimists are not as anxious prior to performance, would prefer not to think about possible negative outcomes before beginning a task, show performance facilitation when overtly encouraged, and deny having control over failure performances relative to success performances (Cantor & Norem 1989).

Another personality disposition, mentioned in the literature as influencing the coping process, was the Type A behaviour pattern (Matthews 1988). Type A incorporates a competitive achievement orientation, a sense of time urgency, and a tendency toward hostility. Glass (1977) characterised this pattern as reflecting a continual attempt to gain and maintain control over significant aspects of one's environment. It seems an easy inference that Type As may prefer active coping and may supports awareness of distress emotions (Matthews 1988). Type As is relatively unlikely to disengage from goals with which stressors are interfering. Another personality dimension was trait anxiety (Spielberger 1972). Trait anxiety is associated with a tendency to become preoccupied with distress emotions when under stress. High trait anxiety may also predict unwillingness to engage in active coping and a tendency to disengage from goals (Carver 1989).

Archer (1979) studied the interaction of trait anxiety and expectancy of control in a shock-avoidance experiment. Under clearly defined conditions, subjects with high trait anxiety and subjects with low trait anxiety did not differ with respect to their expectancies of control. However, there were differences in the ambiguous condition; persons with low trait anxiety reported a significantly greater expectancy of avoiding shock than did those with the trait anxiety. In other words, a personality trait variable (trait anxiety) was found to be influential in the ambiguously structured condition but not in conditions that contained clear and explicit situational cues (Folkman 1984).

1.4.4.2. Illness-related factors

Another factor that influence coping process, reported by Cohen and Lazarus (1973), is the seriousness of the medical condition. In effect, if seriousness of medical condition is a prime factor in affecting recovery and it also affects how much information the patient is told or seeks out, any relationship between the patient's knowledge of his medical problem and recovery would, in fact, be controlled by the seriousness of the medical condition. Seriousness of medical condition has a bearing on coping classification and possibly on recovery. For example, a patient who discovers he has a more severe condition could become more vigilant about his operation than the patient with a routine medical problem.

In heart transplant the severity level of the physical illness appeared to have a major influence on coping outcome, both before and after heart transplantation. The more a patient is tired, exhausted and breathless due to cardiac failure, the more the repertoire of psychological coping mechanisms appears limited, and seemingly of limited efficacy, for these patients are frequently severely depressive and anxious (Zumbrunnen, 1989). This finding is consistent with the study of Dew et al (1994), which emphasise the role of the critical physical health history as predictors of distress in post-transplantation. Physical health factors, requiring circulatory support (indicating poorer cardiac status) and treatments related to long term post-discharge transplant course, remaining hospitalized longer post-transplantation, would influence psychiatric distress levels over time.

1.4.4.3. Social factors

Additional important domains of psychosocial vulnerability that are identified in the literature concerned social supports and losses. Findings of these studies emphasized the significance of the primary family caregiver in influencing and moderating the patient's psychological adjustment following life-threatening health events, including organ transplantation (Mishel & Murdaugh, 1987; Caine & O'Brien, 1989; Dew, et.al., 1994). The availability of social resources support the coping process and affect the severity of the disorder by mediating the impact of stressor (Billings & Moos, 1982; Lazarus, 1981).

Dew, Simmons, Roth, Schulberg, Thompson, Armitage & Griffith (1994) also suggest that the strength of the relationship between caregiver support and heart transplant recipient well-being, as found in their study, underscores the importance of intervention efforts that involve the caregiver in education and counseling on both the specific physical health considerations involved in post-transplantation care and the more general management of organ transplant related stress on the family. Simmons et al (1987) found that heart transplant recipients' psychosocial environment once they returned home after the transplant-the environment in which they are living as they adjust to the transplant-would influence their subsequent long-term psychological well-being.

As Lazarus and Folkman (1984) stated, one of the antecedents theorized to affect stress and coping is social support. Social support as suggested by House (1981) is not a unitary concept but multidimensional. Social support can be defined in terms of the functional types of support, for example, emotional, tangible and informational (Cohen and Wills, 1985). According to numerous studies, social support appears to

enhance effective coping (Cobb, 1976). According to the buffering hypothesis (Cohen and McKay, 1984) psychological stress has negative effects on the health and well-being of those with little or no social support, but these effects are lessened or are eliminated for these with stronger support systems. They also pointed out that possible stress buffering mechanisms of social support may intervene between the stressful event and outcomes. Social support may intervene between the appraisal of threat and the outcome, by providing a solution to the problem or reducing the importance of the problem that would be encompassed under coping responses. In a study by Gore (1978) social support affected the appraisal of threat and buffered people against stress by helping them to redefine a situation as less threatening.

According to Lazarus and Folkman's (1984), the resource, perceived availability of social support, is important in the stress and coping process both as an antecedent directly influencing the degree of threat and as an antecedent influencing coping responses. Lazarus and Folkman (1984) also contented that not only is the resource of social support evaluated for its availability, but also its effectiveness in the particular situation in determining its use. Eckenrode (1983) stated that most researchers assume that use of social support represents an effective coping strategy that will result in more positive outcomes following exposures to stressors. Such an assumption, however, ignores the actual costs associated with using social supports. There is evidence of an apparent negative impact of using social support to deal with problems, in contrast to the beneficial effects of working things throughout by oneself (Pearlin and Schooler 1978). Moreover, particularly with functionally disabled subjects, the finding may merely reflect a relative inequality of exchange between the provider and the recipient presenting obligations or depths to correspond to the benefits (McNett 1987).

According to Schaefer, Coyne, and Lazarus (1982) perceived personal constraints may dilute the beneficial effects of social support and, thus, weaken any relationship with outcomes. This would account for some of the equivocal results of the stress-attenuation studies. The presence or lack of constraints to the use of social support or network orientation is important in the perception of stress, preference in coping responses, and coping outcomes.

Findings by Billings and Moos (1981) supported the influences of social support on coping responses. Moreover, individuals in supportive families engage in more problem-focused coping and less avoidance coping than individuals in less supportive families (Billings and Moos 1982). The availability of social resources would promote adaptive coping efforts and discourage avoidance strategies (Holahan and Moos 1987).

A number of studies have actually shown that subjects who have a good deal of social support are less vulnerable to psychological disorders. Environments, which are not supportive and which, at the same time, are a source of considerable social stress, would hinder psychological adjustment and increase the risk of the patient's becoming a "psychological and social invalid" (Cobb 1976; Cohen and McKay 1984; Holahan and Moos 1981).

Social resources are positively associated with physical and mental health (Heller and Swindle 1983, Moos and Mitchell 1982) because they provide emotional support, tangible assistance, and informational guidance. In this regard, persons with more social resources are less likely to use avoidance coping strategies for instance, women who have little family support are more prone to engage in avoidance coping

(Cronkite and Moos 1984). In turn, the use of avoidance coping is linked to more family conflict (Moos and Moos 1984).

The stress and coping paradigm points to social support factors (for example, in formal social networks and relationships with intimate partners and family members) as resources for managing stress and maintaining health (Heller and Swindle, 1983). Several theorists have noted the paucity of social support available to many depressed persons. This paucity may be due to depressed persons' lack of necessary social skills to develop and use social resources (Lewinsohn 1974; Weissman and Paykel 1974) or their behaviour eroding existing support from friends and family members (Coates and Wortman 1980; Rubinstein and Timmins 1978), or as a factor causing depression. Brown and Harris (1978) found that, for women exposed to recent negative events, the absence of a supportive and intimate relationship with a significant other person (typically a husband or male friend) increased the probability of an onset of depression.

As people experience a chronic life stress, one of the ways they attempt to cope is by seeking various kinds of support from their social network. A network can be perceived both as helpful and as not meeting certain support expectations. To the extent that expectations are not met, people experience more stress, are more likely to be depressed, and to report low overall satisfaction with their network support. There may also be a feedback loop wherein people who are more depressed are asking for more help and hence increasing the likelihood of having more upsetting experiences of unmet expectations, more stress, etc. The degree of upset experienced in relationship to network members in any area of support, either as a result of their negative input or their not meeting the person's expectations of

support, has been shown to affect the severity of depression (Fiore, Becker, & Coppel, 1983).

Other factors mentioned in the literature as affecting the coping process were: the coping repertoire, controllability of the stressor, and the existence of multiple stressors.

1.4.4.4. Coping repertoire

According to Pearlin & Schooler (1978), the kinds of responses and resources people are able to bring to bear in coping with life-strains make a difference to their emotional well-being. And it is equally apparent that there is no single coping mechanism so outstandingly effective that its possession alone would insure people's ability to fend off the stressful consequences of strains. Having a particular weapon in one's arsenal is less important than having a variety of weapons. Perhaps, effective coping depends not only on what people do, but also on how much people do. Using fewer coping responses and possessing fewer resources maximizes the probability that strains will result in emotional stress, and being able to call on more of these mechanisms minimizes the chances. Folkman (1984) and Mitchel, Cronkite and Moos (1983) propose that the optimal coping style consists of the largest possible repertoire of coping responses, both problem- and emotion-focused.

1.4.4.5. Controllability of the stressor

Another variable that previous research has linked to variations in coping is the controllability of the stressor. When situations are controllable, active coping strategies predominate, when situations seem less controllable, alternative strategies predominate (Folkman and Lazarus 1980, Scheier, Weintraub, & Carver, 1986). Rotter (1966, 1975) conceived of generalized control expectancies as having their greatest influence when a situation is ambiguous or novel. Under conditions of ambiguity which is used here to refer to lack of clarity in the environment, situational cues regarding the nature of the outcome and/or the extent to which it can be controlled are minimal. In the absence of clear information, the situation is like a projective test, and the person makes inferences based on general experience and personality dispositions, which include beliefs, to understood what is happening. The greater the ambiguity, the more inference is required and, consequently, the more influence person factors have in determining the meaning of the environmental configuration (Lazarus, Eriksen 1951; Schank & Abelson, 1977). When a situation is highly ambiguous, a person with an internal locus of control might be expected to appraise the situation as controllable, whereas a person with an external locus of control might appraise it as uncontrollable. However, when a situation is not highly ambiguous, it would be expected, as noted by Rotter (1966, 1975) that judgments about controllability would be influenced more by situational characteristics than by generalized beliefs (Folkman 1984).

According to Folkman and Lazarus (1980), ambiguity can intensify the threat because it limits the individual's sense of control. Within a highly uncertain situation, coping processes are limited because the focus of action is unclear.

1.4.4.6. Multiple stressors

The literature suggests a specific aetiological relationship between recent life events involving personal loss-for example, loss of important relationships with others through divorce or death-and subsequent depression (Paykel, et.al., 1969; Brown and Harris, 1978; Finlay-Jones and Brown, 1981; Dew, et.al., 1992). Dew's et al' (1994) findings emphasise further the potential for deleterious mental health effects when multiple stressors-in their study, transplantation plus additional major life events- co-occur during a limited time period. In their study, it was found that the experience of other major life events during the same time period as the transplantation was also associated with elevated depression levels.

The above studies considered a number of factors influencing the coping process. Coping seems to be a very complicated process influenced by all these factors that described previously. Better understanding of not only which factors, but of the mechanisms whereby they may foster vulnerability, may help to the continued development and application of strategies to assist heart transplant recipients in their adjustment to postoperative life.

1.4.5. Interventions to enhance coping

Two studies have examined the effects of interventions that consisted of instructing patients in the use of a coping strategy. Lindemann and Van Aernam (1971) compared the postoperative course of surgical patients who received preoperative instruction in postoperative activities, such as deep breathing and ways to move that minimize pain, with those who did not receive such instruction. The

patients who received instructions in activities to perform post-operatively had shorter postoperative hospitalizations than the control group.

A study of male heart surgery patients by Henrichs (1971) focused on psychological process. In this investigation the effect of systematic relaxation, as a specific coping strategy, on the occurrence of impairment of consciousness, such as illusions or hallucinations, was examined. The experimental patients were taught before surgery to systematically relax with the aid of a tape recording. The recorder and tape were available to patients post-operatively and they were instructed to use the technique 4 times a day. The patients in the control condition received the standard care provided to all patients. Fewer of the patients instructed in the coping strategy showed signs of impairment of consciousness as compared with the control patients. Thus, instruction in a specific coping strategy relevant to affective reactions appears to reduce psychological reactions. Both the Lindemann and Van Aernam (1971) and Henrichs (1971) studies provide support for the conclusion that interventions consisting of instruction in a coping strategy bolster patients' ability to cope with the postoperative experience (Cohen and Lazarus 1973). Zumbrunnen (1989) suggests that all therapeutic interventions are aimed at enhancing the patient's coping abilities. Pharmacotherapy is sometimes used as an external aid for mastering major anxiety, affective or organic disorders (Folkman and Lazarus 1984). Various psychological interventions have been described and recommended: firstly emotional support from the therapist, and incentive to seek support from other sources (family, physician, God). Supportive therapy is probably the most frequently used and maybe the most appreciated aid provided by therapists (including by the surgeon and by the nursing staff) to patients facing a vital danger (Baudin 1989; McAleer 1985).

Different forms of specific interventions have also been described: individual, marital/family (Gier et al, 1988) or group (McAleer 1985); different theoretical orientations: cognitive-behavioural (Gier et al, 1988), psychoanalytical (Baudin 1989), or more often eclectical (Gutkind 1988) including stress reduction techniques (Gier et al, 1988), verbalization of hidden feelings (Christopherson 1987).

Cifani and Vargo (1990), who made a research review in teaching strategies for the transplant recipient, found that effective preoperative teaching can significantly alter patient compliance and promote optimal self-care in the postoperative period.

The role of support groups (McAleer, et.al., 1985; Suszycki, 1988; Hyler, et.al., 1985), in heart transplant programs, is to provide information, allay feelings of isolation, sharing of experience, and ventilation of painful affects; and may be a vehicle for important feedback to the transplant program about patient needs, problems and complaints (Shapiro, 1990).

Zumbrunnen (1989) also mentioned that investigation of coping mechanisms proved useful as an approach to the therapeutic dimension. For example, a patient whose coping strategies were limited to a few mostly self-directed mechanisms, insufficient to master a major pre-transplantation anxiety, was encouraged to seek help, affection and information from others, especially his wife and his doctor. On the other hand, other techniques enhancing coping skills proved useful in the pre- and peri-transplantation phases: providing precise information on the transplantation process, including through contact with peer patients candidates and transplanted patients. Under the guidance of the psychiatrist, a preoperative visit is organized to the intensive care unit, where the patient stayed in isolation after the heart transplantation, in order to arrange a meeting with the medical and nursing staff

previously to the operation. This preparation for the operation through cognitive anticipation and role rehearsal was aimed at the prevention of stress reactions in the peri-transplantation phase. In the same manner, the medical staff were sensitized to the risk of affective differentiation related to postoperative isolation, and invited to tolerate and encourage frequent visits from the patient's family during the isolation phase.

According to Leventhal et al (1980), there is a need to provide an educational intervention in heart transplantation to guide a perception that is more compatible with chronic self-regulation. The Common Sense Model developed by Leventhal et al (1980) is particularly suited to such interventions because it focuses on impacting aspects of the representation that influence behaviour and emphasizes the need to present both abstract information about a health threat and more concrete coping skills to be able to carry out the behaviours. The model places emphasis on the subjective nature of perception about health threats and the dynamic relationship between perception and coping. The Common Sense Model of illness (Leventhal et al., 1980) was used as a theoretical framework for measuring perceptions and beliefs about the heart transplant experience in a study about heart transplant recipients by Baumann et al (1992). This self-regulative model of behaviour suggests that information about health threats consists of three sets of component process: 1) representation, 2) coping or action plans, and 3) appraisal. Leventhal (1989), notes that these sets of variables have typically been treated as distinct stages in a linear sequence for processing information. However, it may be more valid to treat them as components with the assumption that they operate in a state of constant interaction rather than in only one sequence. So the main limitation of the model is that its goal is to describe the components of representation, coping, and appraisal of an event, neglecting their relationship and interaction.

The Neuman system model (Neuman, 1985) is a model to understand coping strategies and the basis of organizing nursing interventions. The Neuman systems model has its central focus on the holistic view of person or client, from both a philosophic and biologic perspective, which implies relationships, dynamic freedom, and creativity in adjusting to stress situations occurring in the internal and external environment (Neuman, 1985). According to Neuman, health and wellness results when the person, in constant interaction with and adjustment to environmental stressors, achieves harmony or stability. According to Neuman, the purpose of nursing interventions is to facilitate the client's optimal wellness potential, resulting in stability or harmony of the client system, either as retention, attainment, or maintenance of wellness. The prevention-as-intervention modes are used within the framework of primary, secondary, and tertiary prevention. Neuman's model could be used as a way of understanding the effect of stressors and the interaction between stressors and the person and the way nursing intervention could be organized.

However, Neuman's model seems difficult to be applied for suggesting interventions to heart transplant recipients. Neuman's model provides an emphasis to the client's physical health and not the psychological health; more emphasis is placed on the physiological dimension of the person. As it was found in this study, whether a stressor can be harmful for a heart transplant recipients depends very much on his perception as such and consequently on his psychological health.

Another issue is that even though primary, secondary and tertiary prevention are identified, it is not clear why other intervention actions are excluded. Cognitive-behavioural interventions may be proved useful in primary prevention by identifying and reducing the significance of possible risk factors. Such intervention can be applied in tertiary prevention by helping the patient to use all appropriate internal and

external resources for optimal wellness. Neuman also suggests health education strategies in the primary prevention. Health education strategies are not always the right answer to prevent a stressor; for example, as discussed in the findings of this study, when heart transplant recipients feel anxious before a biopsy, providing information or guidance about the procedure, might force the patient to encounter with additional stressors.

In primary prevention, Neuman, suggests to identify and reduce the possibility of encounter with the stressor. Neuman (1989) describes the ideal, not to prevent coming into contact with the stressors, but to prevent or reduce a possible reaction within the system. This consistent with Selye's (1956) theories on which much of Neuman's work is based. But in this way she accepts the stressor as inevitable. Another way to prevent the stressor may be to make changes in the environment and to create the context where the stressors will not occur. That is to help the patient to gain personal control over the situation so to make the stressor more "invisible", or to help the patient to change his perception of the stressor as less threatening.

According to Newman it is important to focus on strengthening the flexible line of defense to prevent a possible reaction. This process requires an assessment of what meaning an experience has to an individual in the present as well as some knowledge of his past coping patterns. Even though the meaning attached to the experience and the past coping patterns proved to be important factors in coping process, Newman seems not to account the importance of the present coping skills employed by patients. Generally in Neuman's model emphasis is not given to the role of coping in the wellness of the person. For example, as one of the goal of Neuman's theory, is to improve the client's ability to cope and consequently prevent potential invasion of stressors, more emphasis may be needed on how to improve client's ability to cope

and how the utilization of what coping skills can prevent invasion of stressors. Neuman also seems to accept that there are two extremes in interaction of the person with the stressors, either harmony and stability or disorganization and death. She seems to neglect the possibility of situations that involves negative emotions and might be accompanied by sadness, anger and depression that are normal in many illnesses and patients must cope with them. The possibility of maladaptation seems not to be well emphasized.

All the above issues make Neuman's model not to be applicable with populations like the heart transplant recipients for which perceptions and coping play an important role in their adaptation or maladaptation to their experience. In order to measure heart transplant recipients' adaptation, modifications of Newman's conceptualization and measurement of health might be useful.

The role of cognitive therapy (CT) (Beck, 1967), as an intervention can emphasize belief and attitude change as the fundamental process leading to effective coping. The CT approach discussed by cognitive therapist Ellis (1962) as rational emotive therapy, Meichenbaum's (1977) as self-instructional therapy and Beck (1976) as cognitive therapy. Albert Ellis' (1962) rational emotive therapy is a good example of a cognitive behavioural therapy. Ellis adopts the view of the Greek philosopher Epictetus as a central assumption in his therapeutic approach. Epictetus proposed that, "man is disrupted not by things but by the views he takes of them". Ellis therefore regards emotions and behaviours as the products of beliefs rather than direct responses to the environment. Thus, instead of trying to change the environment, emotional disturbance may be alleviated and maladaptive behaviour eliminated by changing people's internal representations.

According to D'Zurilla and Nezu (1982) Ellis' approach focuses on the underlying beliefs, the premises that contribute to a subject's thinking and maladaptive behaviours. The goal of treatment is the replacement of irrational beliefs and illogical conclusions with rational beliefs and logical conclusions. A variation of Elli's procedure is Meichenbaum's cognitive restructuring theory of self-control (Meichenbaum, 1975). Meichenbaum gives less emphasis to the logical analysis of irrational beliefs. He argues that it is not the incidence of irrational beliefs per se that distinguishes normal from abnormal populations, but rather that the two populations differ in the coping response they make to their irrational thoughts. Beck (1967) has also argued that dysfunctional emotions such as anxiety and depression follow from people's perceptions and evaluations of the events in their lives rather than from the events themselves.

Constructive action is perhaps best seen as an effective response to depression. Referring to the general biopsychological model discussed by Hanson and Gerber (1990) patients are taught to view depression as involving an interaction among emotional, mental, behavioural, and even physiological elements. Once depressed affect takes hold, irrespective of the cause, the person's physiology, thoughts, and behaviours are all influenced in a way that reinforces and perpetuates the depression. In particular, thinking tends to become distorted, and activity diminishes. Physiologically, the person may experience loss of energy, fatigue, appetite changes, and a variety of unpleasant somatic sensations. Vicious cycles are created that serve to maintain the depression. It then becomes extremely difficult to modify directly one's depressed mood, negative thoughts, distortions, and associated physiological sensations. The greatest possibility for change is in the action component. Unfortunately, most depressed people do not want to do anything because they do

not feel like doing anything. It is as though they are waiting to feel better (not depressed) before they can engage in constructive action.

Constructive action as a response to depression may be approached from the perspective of Morita therapy principles (Reynolds, 1984). Reynolds has described Morita and other Japanese forms of psychotherapy. Along with some behavioural approaches, Morita therapy emphasizes action as the principal way of managing negative feelings. People who focus excessively on their feelings become unable to live productively. Patients are encouraged to concentrate on behavioural goals. Feelings are viewed as ephemeral phenomena that are too changeable to form the basis of individual behaviour. Therapy is aimed at helping individuals identify paths to life goals and to encourage patients to ignore feelings that would interfere with the behaviours necessary to reach these goals. Morita therapy encourages focusing on the world outside the individual and emphasizes that pleasure in life is the result of productive activity. Morita principles have some obvious similarities to certain fundamental ideas of cognitive-behavioural theory including its emphasis on problem solving, identifying purposeful behaviours, and de-emphasis of trying to alter negative emotional states directly. Morita therapy also strongly encourages a rational, realistic appraisal of situations that is strikingly similar to what is found in the writings of cognitive-behavioural theories such as Ellis (1962) and Burns (1980). The constructive action perspective encouraged by Morita therapy adapts well to the self-management approach to many of the problems accompany a heart transplantation.

As it was found in the literature, a number of treatments designed to alleviate depression, such as various forms of cognitive-behavioural therapy, can be conceptualised as interventions of facilitating the use of appropriate coping strategies

(Meichenbaum & Cameron 1983). A few studies have evaluated the impact of interventions designed to teach coping skills to patients experiencing pain (Turk et al., 1983) or undergoing various surgical procedures (Langer et al., 1975; Leventhal & Everhart 1979). As Kessler and colleagues state (1985), if an individual is coping with life-threatening illness with minimization or denial, experimental treatments that expose respondents to information, or encourage active coping efforts, may be detrimental.

Interventions programs may focus on lessening the prevalence of a stressor, helping heart transplant recipients avoid conditions that lead to stress, changing the appraisal of a stressful experience, or providing information to alert recipients to the tasks they will confront and to potential coping strategies for managing them.

1.5. Conclusions

The background literature highlighted the paucity of information about the nature and the meaning of recipients' experience of the post heart transplantation period.

The search of the literature proved that qualitative information, which could give insight into the meaning of experience and perceptions of the post heart transplant period, is limited. Despite an extensive literature search no research was discovered that describes the recipient's experience in coping with the post-operative period.

Qualitative research was understood in this study to be the appropriate approach to attempt to uncover the nature of heart transplant recipients' experience and ways of coping post-operatively, and to understand what lies behind the phenomenon about which little is yet known.

Because limited research has been conducted on the coping with heart transplant post-operatively, significant gaps in what coping skills are used, what influence the selection of these coping skills, and what is the role of coping in recipients adaptation, remained in one's understanding. Understanding why recipients cope the way they cope, was responsibility of a qualitative method to discover through detailed data from recipients' descriptions of their thoughts, feelings and attitudes. Qualitative methods needed to be used in order to gain novel and fresh slants on the coping process and recipients adaptation to the postoperative life, about which little is already known. Understanding the problems experienced and coping strategies used, health care providers may help recipients' adaptation to the postoperative period and consequently improve the quality of life of heart transplant recipients: by identifying the needs of recipients and areas where help need to be focused.

CHAPTER 2: Methodology

2.1. Introduction

This chapter describes the methodology for the data collection and analysis used in this study. After a brief description of quantitative and a more detailed examination of qualitative research, a description of the reasons is given as to why qualitative research and grounded theory method was used. A description of how data were collected and analyzed is also given.

2.2 Aims of the study

The aims of the study were:

1) To identify the physical and psychosocial problems experienced by heart transplant recipients.

2) To identify coping strategies used by heart transplant recipients.

2.3. Quantitative and Qualitative Research.

Research, according to Morse and Field (1996), fills a vital and important role in society: it is the means by which discoveries are made, ideas are confirmed or refuted, events controlled or predicted and theory developed or refined. All of these functions contribute to the development of knowledge. However, no single research

approach fulfills all of these functions, and the contribution of qualitative research is both vital and unique to the goals of research in general. Qualitative research enables the researchers to make sense of the reality, to describe and explain the social world and to develop explanatory models and theories. It is the primary means by which the theoretical foundations of social sciences may be constructed or re-examined. Thus, qualitative researchers are primarily concerned with the development of description of an observed phenomenon to generate solid theory as an outcome, or the product of their research.

On the other hand, in quantitative research pertinent knowledge from previous research and from everyday life is organized into theory-given what is known and one's best guess about reality-to build a cogent and best argument that may answer the question. This framework is then tentatively constructed as conjectures, systematically tested and subsequently revised in light of these experimental results.

According to Morse and Field (1996), it is important to note that the quantitative researcher is primary concerned with theory testing and the qualitative researcher is primary concerned with the theory generation.

Quantitative Research: Quantitative research, in contrast to qualitative research, seeks causes and facts from the etic or "world view" perspective (Vidich and Lyman, 1994). As Morse and Field (1996) state in this case the findings are based on the researcher's interpretations of the observed phenomena, rather than on the subjects' interpretations of events. Quantitative research looks for relationships between variables so that causality may be explained and accurate prediction becomes possible. The aim is to examine the experimental variables, while controlling the intervening variables that arise from the context. With this control over the effects of

context, the relationships between variables can be generalisable and predictive in all settings, at all times.

Quantitative researchers establish a theory identifying all constructs, concepts and hypotheses while preparing the proposal and before beginning data collection. These concepts are made operational so that the hypotheses may be tested. Concerned with rigour and replication, the researcher ensures that the measurement instruments are reliable and valid. Data are then collected, numerically categorized, and the relationships between the variables used to measure the concepts are established statistically using "hard" (i.e. numeral) data (Morse and Field, 1996; Polit and Hungler 1995). Bias is controlled by randomly selecting a large and representative sample from the total population. Structured instruments, such as rating scales, are frequently used to collect data and are usually administered once, as it is assumed that reality is stable (the variables measured will not change over time). The goal of quantitative research is to test the theory deductively by systematically testing the hypothesis.

Qualitative research: It has been suggested that qualitative methods should be used when there is little known about a phenomenon, when the investigator suspects that the present knowledge or theories may be biased or when the research question pertains to understanding or describing a particular phenomenon or event about which little is known (Morse and Field, 1996). Qualitative methods are particularly useful when describing a phenomenon from the emic perspective, that is the perspective of the problem from the "native's point of view (Vidich and Lyman, 1994). In clinical research the emic perspective may be the perspective of the patient, caregiver or relatives.

The emphasis may be relative to process and meaning, rather than measurement. Ideas are generally seen to be more important than numbers (Melia 1982).

Qualitative researchers sympathize with the view that what is real is a construction in the minds of individuals (Denzin and Lincoln, 1994; Guba and Lincoln, 1994). What could be described as objective knowledge and truth is a result of perspective; and are created in the mind, not discovered. Knowledge consists of constructions about which there is relative consensus at a given time. Therefore, such constructions are subject to continuous revision. Multiple knowledge can coexist when competent interpreters disagree, or there are sociocultural differences (Denzin and Lincoln 1994).

Qualitative research is usually conducted in a naturalistic setting, so the context in which the phenomenon occurs is considered to be part of the phenomenon itself (Hinds, Chaves and Cypess, 1992). Thus, no attempt is made by the researcher to place experimental controls upon the phenomenon being studied or to control the "extraneous" variables, all aspects of the problem are explored and the intervening variables arising from the context are considered a part of the problem. Using this approach the underlying assumptions and attitudes are examined, and the rationale of these are also elicited within the context in which they occur.

As mentioned by Morse and Field (1996), the qualitative approach to understanding, explaining and developing theory is inductive. This means that hypotheses and theories emerge from the data set while the data collection is in progress and after data analysis has commenced. The researcher examines the data for descriptions, patterns, and hypothesized relationships between phenomena, then returns to the setting to collect data to test hypotheses. Thus, the research is a

process that builds theory inductively over a period of time, step by step. The theory fits the research setting and is relevant for that point in time only. These data may largely consist of transcriptions of interviews, and/or observations of the setting. Data of these kinds are meaningful to others and considered "rich" and "deep" (Geertz, 1973). However, these data are hard to manage for the purposes of analyzing and writing a report, as they cannot be relatively transformed into numeric codes for statistical manipulation. In this respect they are often said to be "soft" data (Morse and Field, 1996; Polit and Hungler 1995).

The qualitative research process can be exceedingly time-consuming, both for the collection and the analysis of data. In contrast to quantitative research, the number of subjects in the study is frequently small, and a random sample is not selected. Rather, the researcher selects participants who are willing to talk and have established relationships of trust with the researcher. The collection of in-depth information about some phenomenon might lead to the formulation of hypotheses that could be tested more formally in subsequent research (Polit and Hungler, 1995).

2.4. Qualitative approaches to examine phenomena.

Qualitative data have always been used in the social sciences, particularly anthropology, history and political science, but it is only in recent years the qualitative paradigm has developed a role in health care research (Morse & Field, 1996). Some of the methods that usually being used to examine phenomena qualitatively-phenomenology, grounded theory, and ethnography- will be introduced here in this section.

2.4.1. Phenomenology

The objective of phenomenology is to describe the essence of behaviour, based on meditative thought and with the purpose of promoting human understanding (Omery, 1983). The phenomenological method is both a philosophy and a method (Cohen, 1987). The method originated with philosophy, using the work of Husserl, Heidegger, Sartre and Merleau Ponty. The phenomenological tradition seeks to understand the lived experience of individuals and their intention within their "life world". Phenomenology is, therefore, the study of phenomena and the appearance of things, and the discovery of their essence is the ultimate purpose of such research (van Manen, 1990).

Omery (1983) notes that it is requisite of phenomenology that no preconceived notions, expectations or frameworks be present to guide the researchers as they gather and analyze the data. While the life-worlds of individuals being studied are the primary source of data, literature, poetry or art may be used to gain an understanding of the essence of the phenomena.

Phenomenology accepts experience as it exists in the consciousness of the individual. Phenomenologists, maintain that intuition is important in the development of knowledge, although human meaning cannot be inferred from sense impression alone (Bryan, 1966).

Unlike grounded theory, where the goal is to develop theory, the goal in the phenomenological method is to provide an accurate description of the phenomena being studied. Phenomenology also does not presuppose the existence of process, although process may be discovered as the research takes place. The goal of

phenomenology is to describe accurately the experience of the phenomenon under study and not to generate theories or models, nor to develop general explanation. Many approaches to qualitative research are classified as "phenomenology", if the research focuses on experience. Care must be taken not to take the writer's description of method without question (Morse and Field, 1996).

Phenomenology was found to be not the appropriate method to study the experience of heart transplant recipients. Even though phenomenology focus on the lived experience of individuals, its goal is only to describe the experience. Description only of the heart transplant recipients' problems and coping strategies would not be enough to give an insight and understanding to the coping process.

2.4.2. Ethnography

Historically, ethnography evolved in cultural anthropology and tended to focus on the cultural patterns of village life. Ethnography was incorporated into health care research by nurse-anthropologists, such as Aamodt (1982), Leininger (1969), and Ragucci (1972).

Recently, Boyle (1994) notes that ethnography is always holistic, contextual, reflexive and is presented from the emic perspective. To study a culture, the researcher must spend time in field (Fetterman, 1989). Ethnography is always informed by the concept of the culture, and it is a generalized approach to developing concepts and to understanding human behaviours from the insider's point of view. Description also of the context in which the behaviour occurs is a critical dimension of an ethnographic study.

As Morse and Field (1996) note, ethnography is a means of gaining access to the health beliefs and practices of a culture and allows the observer to view phenomena in the context in which it occurs, thus facilitating one's understanding of health and illness behaviour. Such information is critical to the provision of care, for the key to a health programme is through understanding the culture of its recipients. Differences in perception between the researcher and the subjects can be clarified as they occur and as the researcher gains an understanding of the topic under study from the subject's perspective. Rather than studying people, ethnographers learn from people. They set out to grasp the emic point of view (Spradley, 1979). Boyle (1994) notes, that there are many variations of ethnography, suggesting that while ethnography is a method, "an ethnography" is also the end product of that method.

Even though ethnography could have given valuable information about the environmental factors that influence heart transplant recipients coping and adaptation, it was proved inappropriate method for this study. Ethnography requires to work with people for long periods of time in the naturalistic setting, and the researcher may need to learn about people's history, religion, politics, economy and environment. As the heart transplant recipients were not hospitalized and participated in the study during short visits in the outpatients clinic, the study of this sample it was difficult to meet the requirements of ethnography, that needs prolonged and direct contact with the group.

Additionally as the aim of the ethnographer is to explain the meaning of the common-sense, taken-for-granted aspects of the world being studied, it was proved not to be appropriate method for studying heart transplant recipients' experience. As there was little information of how patients cope with the demands in post-transplant period, the aim of the study was to discover behaviours rather than taking them for

granted. Consequently a descriptive method like ethnography would not be enough to discover heart transplant recipients' problems and coping strategies and to give an insight to the way recipients cope post-operatively.

2.4.3. Grounded Theory

Grounded theory was first developed by Glaser and Strauss (1967) to address issues raised within sociology about the understanding of human behaviour based on the quantitative paradigm and statistically average behaviour. The theoretical base for grounded theory is symbolic interactionism. Symbolic interactionism stresses that human behaviour is developed through interaction with others, through continuous processes of negotiation and renegotiation. People construct their own reality from the symbols around them through interaction rather than through a static reaction of symbols. Therefore individuals are active participants in creating meaning in a situation. Using grounded theory, a researcher seeks to identify patterns and relationships between them (Glaser, 1992).

Grounded theory has its primary purpose the generation of explanatory theories of human behaviour. Such theory is discovered, developed and then verified through systematic data collection and analysis of data related to an identified phenomenon. Data collection, sampling and analysis all occur simultaneously as the study progresses and sampling and further data collection are based on the emerging theory (Glaser & Strauss, 1967). The data collection and analyses are linked at every step of the way. Theoretical sampling is also employed. Theoretical sampling in grounded theory is the process of data collection for generating theory, whereby the analyst jointly collects, codes and analyses data and decides what data to collect next

in order to develop a theory as it emerges (Glaser, 1978). Thus the data collection process is influenced by the outcomes of the emerging analysis. It proceeds through successive stages, which are determined by changes in the criteria for selecting interviewees according to what has been learned from previous data sources. Participants are therefore chosen as needed rather than before the research begins. This sampling is not predetermined but ongoing, dependent on the needs evidenced in the emerging theory.

As Morse and Field (1996) state, data in grounded theory process are generally collected through unstructured interviews and observation. Analysis techniques include constant comparison, in which all pieces of data are compared with other data. While in ethnography the focus is on cultural beliefs and values, grounded theory is process-oriented and allows for change over time, describing stages and phases inherent in a particular experience.

As Melia (1987) writes, this inductive means of generating a theory is by no means new. Znaniecki described the process of analytic induction in 1934, and elaboration of the method can be found in the work of Robinson (1951) and Cressey (1950). Znaniecki's (1934) analytic induction is concerned with the generation and proof of theories which account for specific phenomena. Glaser and Strauss (1967) offer a systematic means of handling qualitative data, namely, the "constant comparative method"; but this method does not insist upon universality or proof. Glaser and Strauss (1967:39) argue that: "Generating hypotheses requires evidence enough to establish a suggestion-not an excessive piling up of evidence to establish a proof and the consequent hindering of the question of the generation of new hypothesis". The intention is to generate and suggest, but not test hypotheses.

The constant comparative method of data collection and analysis is used in grounded theory. According to Strauss and Corbin (1994), data collection are directed by the process of "constant comparison", where all parts of the data are compared with each other, to observe if they suggest patterns or conceptual categories for the purpose of generating theory. The researcher seeks out the multiple similarities and diversities which exist between instances, cases and concepts, to ensure that the full complexity of the data is explored. The evidence from which a category develops is used to illustrate its concept. The data are being examined closely for all instances of phenomena that seem to be similar, whether or not there is a fit with the developing category.

The advantages of using grounded theory are that it promotes formulation of theoretical accounts and explanations which conform closely to the data collected, as the outcomes are grounded in the data. The theory is, therefore, likely to be meaningful, useful, and understandable to individuals in the situations studied, and is, ultimately, open to comment, correction, refutation or acceptance by them (Turner, 1981; Strauss and Corbin, 1990; Morse, 1994).

Although, the theories are rich in meaning and may be relevant to a particular setting it may not be known if they will be supported in other settings with other populations. Establishing the theory's generalisability to other situations becomes part of a wider comparative analysis (Glaser and Strauss, 1967). This serves two main purposes. First, it delimits the theory's boundaries of applicability; and, second, it may help to broaden the theory, increasing its explanatory and predictive power. Glaser and Strauss (1967); and Strauss and Corbin (1994), place emphasis on theories as process. They stressed that grounded theories are interpretations made

from given perspectives and are contextually and temporally bound. Modification of the theory may be required as reality changes over time.

2.4.4. Conclusion

In summary, the selection of the research approach depends mainly on two factors; that is the nature of the phenomenon to be studied and the maturity of the concept as to how much has already been investigated or is known about the topic, which is usually indicated by the amount of information available. However, a qualitative versus quantitative debate of competing paradigms is reported in the literature (Smith and Heshusius, 1986; Duffy, 1985; Goodwin & Goodwin, 1984; Smith, 1983). Fortunately, since the early 1990s, both "sides" have come to appreciate the role of the other in developing knowledge, and a new trend of combining qualitative and quantitative research has emerged. Nevertheless, it is important to remember that both qualitative and quantitative methods are merely tools for solving research problems. It is the responsibility of the researcher to be wise enough to be able to recognize when appropriate qualitative or quantitative methods should be used, according to the type of research question and the goal of the research process (Morse and Field, 1996).

2.5. Justification for the use of qualitative research and grounded theory in this study.

As in all research, the choice of data collection depends on the goals, objectives, priorities of the investigation, and the level of knowledge available about the phenomenon in question.

According to Strauss and Corbin (1990), one of the main reasons for doing qualitative research is the nature of the research problem. Some areas of study naturally lend themselves more to qualitative types of research; for instance, research that attempts to uncover the nature of a person's experiences with a phenomenon, like illness, religious conversion, or addiction. Qualitative methods can be used to uncover and understand what lies behind any phenomenon about which little is yet known. It can also be used to gain novel and fresh slants on things about which quite a bit is already known. In addition, qualitative methods can give the intricate details of phenomena that are difficult to convey with quantitative methods.

Qualitative research is considered to be ideally suited for the investigation of the phenomenon under study; that is heart transplant recipients' experience, as it may uncover meaningful details of recipients' psychology, feelings, attitudes and thoughts that are difficult to convey with quantitative methods. Also, how heart transplant recipients experience and cope with the postoperative life, is a phenomenon about which little was known, as noted earlier. Measurement of patients' coping was not the aim of the study; it was rather, knowing and understanding how patients cope with the experience in post-transplant period that was the aim of the study. It was believed that qualitative research was the most appropriate method to use in this study, as according to Leininger (1985), it helps the researcher to obtain in-depth

knowledge of human realities and meanings, participant expressions, relevant contexts and intrinsic and extrinsic attributes of human experiences.

Qualitative research methods have been widely recommended as a method of collecting data about people's subjective experience, their views and perceptions (Munhall & Oiler 1986; Somer & Somer 1991; Morse 1991). It is argued that information about recipients' adaptation to the postoperative life and an insight into the coping process with intricate details of how coping facilitates recipients' adaptation, is information that could not be conveyed with quantitative methods.

According to Morse and Field (1996), qualitative questions have particular characteristics. Qualitative inquiry usually answers questions pertaining to what the experience is like; for example, what the experience is like to have a particular illness, as in this study the aim was to explain what the experience is like to be a heart transplant recipient. According to Morse and Field (1996), qualitative research is used to describe how this group of people, who have a particular illness, live and how people cope with their daily lives. The use of qualitative research in studying coping strategies of heart transplant patients does not make assumptions about patients' understanding and provides the reader with a greater understanding and perhaps empathy with the patients.

Qualitative research was understood to be the appropriate approach as the aims of the study were to explore how recipients cope with postoperative life, and to provide an understanding of how and why heart transplant recipients cope the way they cope.

According to Morse and Field (1996), qualitative research is inductive. It does not usually have an 'a priori' conceptual framework or hypotheses to be tested. Rather, as the goal is to develop theory, the researcher must have discovered an interesting topic, and be willing and eager to explore it further to learn about the phenomenon. According to Morse and Field (1996), the outcome of qualitative research is mainly theory. Because the researcher is willing to explore areas that have been relatively neglected by other researchers or to look suspiciously at areas that they believe are perhaps incorrect or in need of modifying, qualitative research has the important role in knowledge development of producing the theory that guides a discipline. Thus, qualitative inquiry provides the theory that ideally directs inquiry within a particular discipline, serving important functions within a discipline. First, the theory may be applied clinically, providing insights that revise or alter clinical practice. Secondly, qualitative findings provide rich description that enables readers to understand and make sense of clinical reality and of otherwise incomprehensible situations and behaviours. In summary, unlike quantitative research where the researcher's emphasis is on testing a theory, the qualitative researcher's emphasis is on the construction of the theory.

In this study of heart transplant recipients coping with the postoperative period, there was not any theory to explain the phenomenon that could be tested. Therefore the goal of this study was to construct a theory to explain the phenomenon. Providing an insight into heart transplant recipients' problems could assist health care providers to understand recipients' needs and the psychological implications of heart transplantation enabling them (health care providers) to focus the emphasis of the care where it is needed. By providing an insight into the coping process it can enable health care providers to develop interventions to help recipients in their effort to cope effectively.

As Coyle et al (1994) state, qualitative research methods are particularly suited to certain types of inquiry. One such context arises when the research topic is especially sensitive and could potentially spark considerable distress in participants such as recipients' experience of heart transplantation. The investigation of such a topic requires sensitive, one-to-one interaction between the researcher and the participant to elicit honest reporting and to reduce the chances of major distress occurring.

Grounded theory is most useful in studying areas in which little previous research has been conducted and in gaining a new viewpoint in familiar areas of research (Stern, 1994; Chenitz and Swanson, 1986). Denzin (1970) makes the point that all data, qualitative or quantitative, serve four functions for theory: to initiate new theory and to reformulate, refocus and clarify existing theory. The grounded theory method serves each of these functions well. If little is known about a topic and few adequate theories exist to explain or predict a group's behaviour, the grounded theory method is especially useful. Interventions resulting from grounded theory may result in the improvement of patient care (Morse & Johnson, 1992; Wilson, 1989; Glaser & Strauss, 1965, 1968).

Grounded theory was understood to be the appropriate method for the collection and analysis of data for this study as it could initiate new theory. The development of a theory to account for the patient's ways of coping with his/her life after the transplant was the aim of this study. It was anticipated that a theory could suggest pertinent factors necessary to ensure appropriate care for heart transplant recipients. A theory could also act as a foundation for further refinement and elaboration of the coping process, as well as to provide a framework for future investigation: through the identification of variables and the generation of hypotheses.

Grounded theory methodology is recognized as a research strategy to address gaps in information and to gain understanding from the subject's point of view (Corbin and Strauss, 1985). Because limited research has been conducted on heart transplantation post-operatively, significant gaps in what problems are experienced, how recipients cope and what influences the coping process, remain in one's understanding of the adaptation process to heart transplantation. Grounded theory was found to be the method ideally suited to gain information about recipients' adaptation to the postoperative life and to gain an insight into the coping process with intricate details of how coping facilitate recipients' adaptation, were information that could not be conveyed with quantitative methods.

2.6. Grounded Theory as was used in this study.

A form of qualitative research, grounded theory, was used in subject selection, data collection, and analysis for studying heart transplant recipients' experience. Rather than being a specific method or technique, Strauss (1987) referred to grounded theory methodology as a style of doing qualitative research that includes theoretical sampling, constant comparative method, and use of a coding paradigm. The purpose of using grounded theory methodology was to discover categories and properties of a phenomenon which would emerge from the recipients' reports and to generate a theory that explains the phenomenon.

2.6.1. Sample

The sample consisted of 42 patients who had undergone a heart transplantation, at a hospital in the West of Scotland. Subjects ranged from one month up to three years post-operatively prior to data collection.

All recipients who had undergone a heart transplantation from the Cardiac Transplant Unit's opening in 1993 were invited to take part in the study. Of the 68 recipients at the time of data collection, 42 agreed to participate in the interview study. A further 9 patients died and the others (n=17) declined to take part in the study. This represents a 62% response rate.

From these 42 recipients who agreed, 30 were interviewed only as analysis of the data indicated a need to include the opinions of 'recently transplanted' patients. For example it became apparent that one of the themes being pursued, that of 'why there were three different accounts of the way heart transplant recipients felt post-operatively', would be better served if it could be explored with recently transplanted recipients. Therefore, in addition, another 12 recipients were interviewed from a population of 18 who were added to the list of recipients during data collection and who had all agreed to take part in the study.

The sample size was decided according to the theoretical sampling. It was after 30 of the 42 "old cases" patients and 12 of the 18 "recently transplanted" patients had been interviewed that saturation of the categories achieved and consequently the sampling process stopped. According to Glaser and Strauss (1967) an *a priori* sample size determination is not made, but instead data collection and analysis continue until the categories become saturated, that is when no new information is

appearing. As Stern (1994) suggested, the well-schooled grounded theorist never, ever makes excuses for the size of the sample or its characteristics. The total sample consisted of 42 subjects, 7 of whom were women and 35 men. They were all Scottish and had the ability to understand and speak English, and nobody was excluded on ethical grounds. Subjects were between the ages of 32 to 61 years old.

Theoretical sampling was the approach used in selecting the participants, in accordance with the idea that emergent categories dictate the direction and nature of further data collection by allowing the categories which emerged from the early interviews to determine the topics covered in later ones. As in grounded theory (Glaser and Strauss, 1967), the researcher proceeded to sample until the data obtained in this study were rich, meaningful, and accurately reflected participants' experiences. Participants who had undergone a heart transplantation, between one month and up to three years prior to the data collection and who had agreed to take part in the study were selected to participate in the interviews and to discuss a range of experiences since their operation. From these interviews the researcher identified theoretical categories of how heart transplant patients cope with the postoperative demands. The initial decision about data collection was based on the research area, not on a pre-conceived theoretical framework.

Further data collection was guided by gaps and questions in the emerging theory. Sampling continued until participants' responses became redundant. Thus theoretical saturation of categories was achieved (Glaser & Strauss, 1967). Theoretical sampling was used because what proved to be important, was what directed the development of the study, rather than precisely where the data came from. The ideas which the interviews produced in the early stage of the study, served to shape the

line of inquiry, and in this way data collection was directed by the theoretical notions which emerged.

2.6.2. Ethical considerations

2.6.2.1. Gaining Access

As the aim of the study was to undertake research involving patients, permission was sought from the Consultant in Charge of those patients and the Co-ordinator of the Heart Transplant Clinic, who had to be informed specifically of any research projects underway involving transplant patients, in order to ensure the safety and the well-being of those patients. Ethical Approval was also sought from the Research Ethics Committee of the relevant Trust hospital and granted (Appendix 1)

2.6.2.2. Informed Consent

Recipients were invited, through letters, to participate in the study (Appendix 2). The letters included a full explanation of the study; the identity and qualifications of the researcher and the organization through which the research was conducted; their rights as participants; and confirmation of ethical approval for the study. Recipients also were informed that they could withdraw from the study at any time, without their treatment being affected. Confirmation was given that all information collected through the interviews would be used solely for the research project and would be treated confidentially.

A reply slip with the consent form (Appendix 3), which was signed by the recipient and a next of kin witness, and a stamped, addressed envelope for its return, were included with the letter.

As soon as the letters were returned, the recipients were contacted by telephone for an appointment. During the telephone conversations, an explanation was given as to how the interview would be conducted and what the respective roles of the researcher and participant would be. Agreement was sought to tape-record the interview. The place, the time and the approximate time-scale of the interview was agreed upon. The date of the interview was chosen so as to coincide with a visit to the Outpatient Clinic. Participants were given the opportunity to ask any questions or to clarify any concerns about the study. The nature of data collection and analysis, according to the rules of grounded theory that require simultaneously collection and analysis of data, meant interviews had to be spaced to allow time to review the data and make adjustments to the research agenda.

2.6.2.3. Ethical considerations in the interview process.

At the interview, confidentiality was stressed, and subsequently maintained. Audiotapes of the interviews were secured in the interviewer's home and at the university. Initials and numbers were used on the transcripts for the reference to a specific person to protect anonymity. Generic terms such as, *the hospital, the health centre*, were used when referring to an institution or organization. Tapes would be destroyed once the thesis had been deemed successful in order to comply with the Data Protection Act (1984).

Before starting the interview, a number of points were discussed with the participants. The researcher:

a) checked that everyone was comfortable and a cup of tea or coffee was offered to the participants;

b) thanked the participants for agreeing to be interviewed and explained how their accounts would contribute to an understanding of the experience of being a heart transplant recipient;

c) reiterated confidentiality and anonymity and discussed the access and storage of the audiotapes. Participants were asked if they had any objection to the audiotapes being kept for possible secondary analysis;

d) explained to participants that the interview could be stopped at any time they wished;

h) described how the interview would develop.

Accounts were facilitated with as little interruption as possible so the participants could control the information and highlight what was important to them. The interview was conducted in a gentle, sensitive manner, with particular attention to participants' needs. Information requested by participants was usually given at the end of the interview.

Most of the interviewees were happy to participate in the study and they were willing to help as much as they could, providing much information, feeling that they could contribute to the success of the study. Many appeared to be anxious as to whether they had given the information needed for the study or whether what they said was enough for this purpose.

None of the participants seemed to have problems with the interview being recorded. Mainly they were happy to talk for about half an hour and it was only in some cases, when patients were reluctant to talk, that they admitted to not knowing which part of their experience might be of interest for the interviewer. After some efforts to ask these patients some questions or to allow them to talk about whatever they considered important in their experience, it was understood that talking was an individual matter that some people tended to find less easy. Thanking them for their time, the interview was terminated.

In three interviews, participants wanted their wives to be present in the interview; and in two of these interviews spouses tended to take over the interviews and talked on behalf of their husbands. Analysis of those data were excluded from the study as they were considered as biased.

Emotional arousal was obvious. In some cases, when participants were recalling painful topics or traumatic experiences, there were often tears. At such times, the tape-recorder was turned off until the participant felt able to continue. The sadness was sometimes compounded by other issues, such as a recent divorce. Participants were always given the option of terminating the interview but, in no case did a participant request that the interview be abandoned. Far more surprising were the interviews which proceeded without emotional arousal and it was not clear how the participant might react later. It should be noted that the researcher checked to see that there was always a member of the clinic staff available to talk to and to comfort the patients after the interview.

Most of the participants admitted feeling happy to have been interviewed and they offered to be interviewed at a later stage if required. Many of them wanted to have a copy of this study when it was completed.

2.6.3. Data collection

The data were gathered by audiotaped, unstructured and in-depth interviews to allow the researcher to "enter another person's world; to understand that person's perspective" (Wilson 1987, p.109). Interviewing is a method of investigation to learn about feelings and thoughts or the way people organize the world and the meanings attached to what goes on in the world. An interview requires asking open-ended questions, listening and recording answers, and then further questioning (Gaskins & Brown 1992).

Data for the study were collected by interviewing heart transplant recipients in one of their regular visits to the Outpatients Clinic. The interviews, which ranged from 20-45 minutes in length, were taped-recorded. The tape recordings were fully transcribed and then coded line by line for the analysis. The initial interviews posed the question: "Would you like to tell me what this experience after your heart transplant has been like for ?" and patients were asked to speak about problems, feelings, thoughts, attitudes, and ways of coping. Interview questions moved from general to the particular. The purpose was to elicit fundamental information in keeping with grounded theory such as dimensions, phases, properties, strategies, consequences, and contexts of behaviour. Using this method, emerging categories were compared with other categories in order to generate ideas about what the major concern of the individual was and how they coped with the concerns. For

patients who needed probes to stimulate their recollections, general questions concerning their thoughts during the post-transplant period were posed (Table 1). These questions were used only in cases when patients need probes to talk and tell their story.

Table 1. Questions to stimulate patients' recollections.

Would you like to tell me about your Heart Transplant experience (problems, feelings, attitudes, thoughts, ways of coping)?
How would you say that having undergone the heart transplantation has affected your life?
How have you felt about these experiences?
Could you indicate what you generally do and feel when you experience stressful events, when you are under a lot of stress (behaviours adopted in attempting to deal with the problem)?
Could you recall any of these problems that you would like to have coped better?
How do you feel now?
How has having undergone a heart transplant affected your relationship with significant others in your life?

As conceptual categories of responses emerged from the interviews, additional questions were asked to help clarify the relationships among the categories. For example questions like, "Could you indicate what you generally do and feel when you are under a lot of stress?" in order to identify how they generally coped with stressful experiences. Trying to identify similarities or differences among the properties of a category or among the categories themselves some other questions were posed. Questions such as, "One person told me that he was more emotional

and open now than he used to be, do you find that your emotions changed after the operation?" were posed in order to refine the definition of a specific category, such as the "Am I a different person now?" category, which included recipients' accounts of the changes occurred in their lives and their personality after the heart transplantation (Table 2). As the interviews proceeded and the concepts emerged, more specific questions, such as thoughts about the donor, were asked.

Table 2. Questions in order to refine a category

People often speak about setbacks or describe the period after the operation as being traumatic. How you would describe that period?
Other patients speak about the importance of having a supportive family/friend that helped them to go through. Do you want to tell me your opinion about this?
One person told me that he is more emotional and open now than he used to be. Do you find that your emotions have changed after the operation?
Some people speak about changes in their priorities after the trauma of the operation. What's your opinion?
Do you usually keep things to yourself or you want to discuss your problem with family or friend?
Patient often worry whether they are going back to normal, back to how they were before. Is this something that worries you?
Some patients said that chatting to your fellow transplant patients help a lot because they are going through the same problems. How do you feel about that?
Patients often are concerned of the extent of the strain they put on their families. How do you feel about this?

In the informal interviews in this study, the recipients described their experience of heart transplant post-operatively. Usually the fore going questions were asked only when patients were reluctant to talk, or they did not know what to say or how to start. When patients were open to talking and the interview was continuing with patients talking fluently about their experience, there was no need of such instructions or questions. This was more close to grounded theory rules that recommend unstructured interviewing without leading questions.

After the opening questions, additional questions were only asked to clarify points made by the patients or to ask the patients to expand on information provided, or to ask them to comment on other patients' reported experiences. Demographic information was not sought during the interviews as all data, according to Strauss (1987), need to earn their way into the grounded theory by being identified as relevant by the patients.

2.6.3.1. The informal interviews

The informal in-depth unstructured interview was found to be the appropriate method to collect detailed and rich data about heart transplant recipients' perception of their experience.

According to Melia (1987), the informal interview allows the interviewer to understand the informants' world from their perspective. The informal interview sits more comfortably among other ethnographic strategies than alongside the more structured versions of the interview found in survey methods. As Melia (1987) states, the informal interview takes the superficial form of a conversation. It is the

underlying structure which distinguishes a purposeful interview from a social conversation. There is a fine balance between basing an interview on a series of research ideas and theoretical possibilities, while still allowing the respondent to introduce new thoughts and concepts. Considerable attention had to be given to the agenda, and the underlying sensitizing concepts which gave some theoretical direction to the interview. This style contrasts sharply with that used in survey analysis. The structured interview seeks to achieve a standardization of data. But the lack of such standardization in the informal interview should not be seen as a threat to the validity of the data. Rather, it is a different means of using the technique in order to produce a full account of the phenomena under discussion. Cicourel's (1964:108) rather acid comment upon the validity of structured interview data serves to underline the fact that what one is looking for in a research method is a match for the problem in hand. As he said: "standardized questions with fixed choice answers provide a solution to the problem of meaning by simply avoiding it."

According to Burnard (1994), the unstructured interview is useful when a researcher is trying to explore, in some depth, a variety of points of view and does not want to be constrained by a particular interview schedule. In the unstructured approach, the interviewer is free to take-up leads, explore issues raised by the respondent and to uncover layers of meaning and perception. In general, the approach has something in common with the client-centred counseling approach advocated by Carl Rogers (1967), in that the interviewer may allow the respondent to take the lead in the interview and allows the respondent's own ideas to structure it.

Schatzman and Strauss (1973:73) describe such interviews usefully:

"The interviewer does not use a specific ordered list of questions or topics because this amount of formality would destroy the conversational style. He may have such a list in mind, or even in hand, but he is sufficiently flexible to order it in any way which seems natural to the respondent and to the interview situation.

The researcher must have defined goals for the interview. Bordan and Taylor (1975:108) say with reference to the interview: *"if you understand your goals, your subject and the interview situation, there is a wide latitude in what you can do. What is ultimately important is not your procedures but rather your frame of reference."*

Informal interviews serve to clarify the meanings the participants themselves attribute to a given situation. Interview questions move from the general to the particular; ultimately, they elicit information fundamental to a grounded theory study such as dimensions, phases, properties, strategies, consequences, and context of behaviour (Hutchinson, 1986).

During the interviews, descriptions of empirical events were kept in memos. The purpose of memos was to write ideas quickly and spontaneously in order to capture connections between the data and to conceptualize ideas. As Hutchinson (1986) states, during the memoing phase, the thinking process is both inductive and deductive. One conceptualizes (inductive) when coding and memoing and then assesses (deductive) how the concepts fit together. Repetitive examination of the data, combined with theoretical sensitivity, aids both processes.

In the interviews for this study, although there was an agenda to help the recipients to talk, they sometimes introduced other topics which they felt were

relevant. A further appeal of this method is its flexibility. Rather than each recipient being asked precisely the same questions, it allowed the interviewer to pursue topics which came up which had some conceptual promise, or indeed to introduce such ideas from earlier interviews to further develop a category. The data were treated as an accumulation of a body of information which were being constantly updated, elaborated, and refined, not as accumulated information to be analyzed at a later stage.

Sometimes it was difficult to know if recipients were telling the story of their experience as they saw it, or as they would have the interviewer believe they saw it. Nevertheless, certain steps were taken to increase the chances of obtaining worthwhile data. In the case of the recipients, two things seemed to be particularly important in this respect: first, that they should volunteer to be included in the study, and second, that they should not see the interviewer as one of the members of the medical team involved with their treatment, and so feel able to trust the interviewer.

According to Hutchinson (1986), grounded theory is conducted in the field, through interviews over a protracted period of time. Prolonged engagement is a step, as described by Lincoln and Guba (1985), that careful qualitative researchers take in order to improve the credibility and establish the trustworthiness of their data and conclusions. Prolonged engagement is the investment of sufficient time in the data collection activities to learn the culture of the group under study, to test for misinformation and distortions, and to built trust with informants. For this purpose the interviewer in this study was involved in the area of investigation long before the data collection commencement; by visiting the hospital, attending the clinics, being introduced to the patients and talking to them, and talking to doctors and nurses finding out more information about the patients and their conditions. Useful

information helped each participant to be treated according to their special condition. Most participants have been introduced to the interviewer long before the interview and this added familiarity to the interview atmosphere as participants felt comfortable and seemed to trust the interviewer.

2.6.5. Data analysis

According to Strauss (1987), the process of doing grounded theory, unlike the other qualitative methods as phenomenology and ethnography, is both systematic and intense, because it requires that the researcher simultaneously collect, code, and analyze the data beginning with the first interview and/or the first day in the field. The method is circular, allowing the researcher to change focus and pursue leads revealed by the ongoing data analysis.

The grounded theory method requires a time orientation that differs from that of phenomenology and ethnography. The generation of grounded theory is inherently circular in nature, requiring an indeterminate amount of time for conceptualization to occur (Hutchinson, 1993).

The tapes were transcribed as soon as was possible after the interview. At that stage the main themes in the data were noted and theoretical notes were made, and transferred onto index cards. According to Schatzman and Strauss (1973), if the researcher wants to go further than the "facts" he/she should write a "theoretical note". These notes represent self-conscious, controlled attempts to derive meaning from any observation. In this way the researcher is able to make interpretations of an observation which has some conceptual future.

The analysis procedure of data was based on the techniques described by Strauss and Corbin (1990) that composed of three major types of coding: a) open coding; b) axial coding; and c) selective coding. According to Strauss and Corbin (1990), coding represents the operations by which data are broken down, conceptualised, and put back together in new ways. The lines between each type of coding are artificial. The different type do not necessarily take place in stages. In a coding session, the researcher might quickly and without self-consciousness, move between one form of coding and another, especially between open and axial coding.

The constant comparative method of joint coding and analysis was used to analyze the data (Glaser & Strauss, 1967). There is an ongoing data collection, coding, and analysis in this type of research. Glaser and Strauss (1967) identified four stages in the constant comparison method: 1) comparing incidents applicable to each category; 2) integrating categories and their properties; 3) determining the theory; and 4) writing the theory" (p.105). Although the stages were progressive, each stage was operational until analysis was terminated. Stern (1980) notes that grounded theory methodology differs from other qualitative methodologies as each piece of data is compared with every other piece (the constant comparative method) rather than describing only the unit under study.

2.6.5.1. The coding procedure

The analysis started with the open coding. According to Strauss and Corbin (1990), open coding is the part of the analysis that pertains specifically to the naming and categorizing of phenomena through close examination of data. That is, the conceptualization of data.

During the open coding process the data were analyzed line-by-line. They were broken down into discrete parts, closely examined, compared for similarities and differences, and questions were asked about the phenomena as reflected in the data. Each sentence was taken apart, and each discrete incident, idea, or event was given a name, something that stood for or represented a phenomenon.

For example in the following transcript, the words or sentences that seemed to represent the same phenomenon were given the name of 'avoiding harmful thoughts'.

*28/3 "I found **I didn't want to see anything hurtful** I couldn't read the paper you know the Bosnia situation **I didn't want to think about it too deeply, I didn't want to hear anything nasty** that there were children being abducted, raped, and all these things I **didn't want to know about it** , it was almost as if I was an open would and it would hurt too much. **I couldn't watch anything for months...I always felt very tender ...I couldn't cope...I didn't really want to know anything** , it was enough just to be coping with my situation".*

By asking questions as "what is this?" and "what does it represents?" all the above incidents were put under the name of avoidance of unpleasant or harmful thoughts.

Later on as the analysis continued, words and sentences that seemed to represent the same phenomenon were coded and given similar names.

*8/9 "**I never thought about the donor** I mean what I thought about was that somebody had given me a gift right enough it was marvelous, I was pleased to have it, **I never thought about the person that gave it to me** well maybe it did cross my*

*mind but **I never really gave it much thought,** I was delighted to have it and it was terrific that someone had done this for me".*

As the analysis and the coding process continued, the phenomena were given conceptual labels as avoidance of unpleasant thoughts, avoiding being hurt, avoiding being involved in unpleasant and harmful thoughts, and avoidance of stressful thoughts.

Once the particular phenomenon in data was identified, the process of *categorizing* was started. All the concepts that seemed to pertain to the same phenomenon were grouped around the phenomenon in order to produce the category. In the previous example, the category was given the conceptual name of "Avoidance". According to Strauss and Corbin (1990) the name of the category should be more abstract than that given to the concepts grouped under it. Categories also have conceptual power because they are able to pull together around them other groups of concepts or sub-categories. The process of open coding stimulates the discovery not only of categories but also of their properties and dimensions. Properties are the characteristics or attributes of a category, and dimensions represents locations of a property along a continuum. Properties and dimensions are important to recognize and systematically develop because they form the basis for making relationships between categories and sub-categories.

Properties of the category were identified as the frequency *("I always felt very tender ." or "I never thought about the donor"),* the extent *("I didn't want to see anything hurtful" or "I didn't want to think about it too deeply"),* the duration *("I couldn't watch anything for months")* and the intensity *("I never really gave it much*

thought, ") of the avoidance. Properties were found often in their dimensional forms as were described before as *always, anything,* and *for months.*

As the open coding helped the identification of categories, their properties and dimensions, the axial coding helped to put those data back together in new ways by making connections between a category and its sub-categories. In axial coding, according to Strauss and Corbin (1990), sub-categories are related to their categories through the *paradigm model.* That is the development of each category (phenomenon) in terms of the casual conditions that give rise to it; the context in which it is embedded; the action/interactional strategies by which is handled, managed, carried out; and the consequences of those categories.

In order to open up the data and develop potential categories, properties and dimensions, certain general questions were asked about the data. Who use avoidance strategies? What makes patients use avoidance strategies? When do the patients use avoidance strategies? How the avoidance help patients? Why is important for patients to use avoidance strategies? Questions like these changed the category of "Avoidance" to a sub-category of the main category "Coping", explaining that Avoidance was one of the coping strategies used by heart transplant recipients. This intense focus on each category helps to show the relationship among data, such as what specific conditions fit with what specific interactions, strategies, and consequences (Strauss, 1987).

Through the axial coding , four main categories with several sub-categories were produced from the data. At this point, links between categories and potential categories also became apparent, by asking questions and making comparisons. During this process of analysis, an original set of about twenty conceptual themes

were combined and integrated by means of comparing items of data, making analytic searches and writing the interpretations of the data until the final categories were formulated. At this stage saturation of the categories was achieved when there was no new conceptual information available to indicate new codes or the expansion of existing ones.

As Hutchinson (1986), states, the researcher continually formulates hypotheses and rejects them if they do not seem accurate. A grounded theorist looks for contradictory data by searching out and investigating unusual circumstances or occurrences. If such data do not fit with what has already been found, they are not discarded but contribute to the richness of the theory in process. Data are compared and contrasted again and again, thus providing a check on their validity. Distortions or lies generated by the participants will gradually be revealed.

Distortions were also found in the data when some recipients reported in the beginning of the interview as not having experienced any problems after their heart transplantation; but later on when they felt at ease, they talked about several problems experienced in the postoperative period. The researcher understood these contradicted data as valuable information, as it was interpreted as recipients' way of coping, denying in the beginning the severity of their condition. This increased the wealth of information available to the researcher, as it added more information and explanations about the role of denial in heart transplant recipients.

In order to evaluate the quality of the data and findings, investigator triangulation was carried out in this study. Investigator triangulation, according to Lincoln and Guba (1985), is the use for multiple individuals to collect, analyze, and interpret a single set of data. Interview transcripts have been given to colleagues and

researchers from other disciplines, for analysis, in order to provide a basis for convergence on the truth and improve the credibility of the research. These people independently categorized a sample of data trying to explore areas of disagreement and help further reduce bias; hopefully the collaboration resulted in a high rate of agreement.

The four categories developed from the data were: 1) "Traumatic experience", 2) "That's a small price to pay for being alive Vs Too big a price", 3) "Somebody else's heart inside me", 4) "Coping".

After the axial coding the procedure of selective coding started. That is the process of selecting the core category, the central phenomenon, systematically relating it to other categories, validating those relationships, and filling in categories that need further refinement and development. A central or core category, "That's a small price for being alive Vs Too big a price to pay for being alive." emerged in the analysis and was the main theme around which other categories were integrated. Again, the relating of categories to the core category was done by means of the paradigm-conditions, context, strategies, consequences. For example the category "Was I prepared for the heart transplant?" was found to represent one of the conditions that give rise to the phenomenon represented by the category "That's a small price to pay for being alive Vs Too big a price". Accordingly the category "Coping" represented the action strategies by which the phenomenon was handled.

In qualitative approaches the researcher is not letting theory drive the research (Morse 1992). As Morse (1996) states, in a later stage of analysis, when the researcher begins to organize the data and to formulate theory, the researcher compares the findings from the setting with established theory and the results of the

research, almost as if drawing a template of other's work over the emerging analysis, to compare the fit. The interplay between theoretical knowledge and the emerging analysis is interesting. The researcher is always acutely aware of the derivation of an idea- an idea found in the work of others or what is the researchers own, arising from patterns within the data. The theory of "Price to pay for being alive: Coping with the postoperative demands" developed in this study which explains heart transplant recipient's experience.

It was found that qualitative data could provide valuable insights into the complexity of the heart transplant recipients' perception of the postoperative period. The Grounded Theory approach to data collection and analysis proved to be appropriate for the research problem. It allowed a substantive theoretical perspective to be derived, which helps to explain heart transplant recipients' experience.

CHAPTER 3: Traumatic experience

3.0. Introduction

The analysis of the data produced four categories which are presented in the following four chapters. The findings chapters are presented according to the importance of the categories as they developed from the study. First is the "Traumatic experience" chapter which describes the first category developed, as almost all the patients wanted to speak first about how traumatic was the heart transplant experience. Then the chapter "Somebody else's heart inside me" describes the second category developed and represents patients' concerns of having somebody else's heart inside them. The chapter "Coping" describes the third category developed, and describes the various and different coping strategies used by the patients in order to deal with these problems. The last finding chapter "That's a small price to pay Vs too big a price" represents the core category that emerged from the data analysis and was the main theme around which the other categories were integrated.

3.1. Introduction to the 'Traumatic experience".

This chapter described the "Traumatic experience", one of the four categories produced from the data analysis, which conceptualised heart transplants recipients' experience. The category "Traumatic experience" started out as a convenient 'handle' to the data concerned with problems such as postoperative medical problems, side

effects of the medication, disturbance of body-image, financial and employment difficulties, marital and family problems, problems caused by hospitalization, and psychological problems that accompany the heart transplant experience. This category is also related to patients' problems caused by not being sufficiently prepared for the heart transplantation and to their concerns about changes occurring in their lives after the heart transplantation, including changes in life and life-style, changes in feelings, attitude, and personality. The development of the category involved several issues which are addressed below, in an attempt to explain, from the recipients' perspective, what problems made the heart transplant experience traumatic. The name "traumatic experience" was given to this category as most of the recipients at interview described their experience of heart transplantation as being traumatic as it involved so many problems.

The "Traumatic experience" category was the first category developed and it was saturated very early in the data analysis as all of the patients wanted to talk about the problems they experienced and most of them described their experience as a traumatic experience.

The sub-categories that describe patients' constructed realities of the heart transplant experience concerning problems, thoughts, feelings, and attitudes are examined in this chapter. Categories are presented using illustrative interview excerpts for explanatory power. For the ease of analysis, the two numbers before the interview excerpts indicate the recipient (the first number) and the second one the paragraph of the transcript. References from the literature are used in order to enrich and show outside support for the concepts of the categories.

3.2. All these drugs !

This sub-category included descriptions of the side effects that patients experienced. Many of the side effects are caused by long term corticosteroid therapy. The purpose of immunosuppressive drug therapy is to interfere with the natural response of the immune system to foreign tissue. The challenge of immunosuppressive therapy continues to be prevention of rejection without excessive immunosuppression, which leads to infection and other complications (Dressler, 1993). Cardiac recipients often receive triple therapy with azathioprine, prednisone, and cyclosporine (Payne, 1992). As Shinn (1980) states, corticosteroids such as prednisone are responsible for insomnia, increasing facial roundness, and for changing bodily appearance as it alters fat distribution, increases protein catabolism of skeletal muscle, and increases appetite as well as sodium and fluid retention. Pain is the result of osteoporosis with associated joint and bone pain. Patients may claim weakness, shortness of breath, or fatigue with no objectively observable basis (Shinn, 1980).

3.2.1. Problems of Altered Mobility.

Alterations in mobility, as side effect of the long term medication, was reported to be a serious problem for heart transplant recipients. Altered or impaired mobility was found in this study to be associated with psychological problems that affected the recipients.

As Lubkin (1990) states, altered mobility affects the total person. He argues that human beings do not experience life solely in physical terms but also in psychological and social terms. Decreased mobility impedes one's sense of independence and productivity and ultimately one's sense of worth and social value. The individual with a mobility alteration has problems that transcend the disease state. A number of psychological and sociological adjustments become necessary. Psychologically the individual must handle loss, face changes in self-image (body image and self-esteem), and overcome fear and stress. Sociologically, family and clients may face role and life-style changes and need to face and resolve differences in perspective.

Pain and loss of energy were described often by heart transplant recipients as overwhelming problems:

6/1 "Physically I was absolutely shattered before the operation and after the operation- after the operation my legs were so weak, I couldn't pull my self up in bed because they were sore ...I remember most I picked up a bed sore as well and every time I was moving from one cheek to the other to get comfortable I slid down the bed and I had to keep calling to the nurses to come in pull me up the bed and it took me a long time to get any strength in my legs".

As Lubkin (1990) says, when mobility is altered, accustomed roles may change or appear to change from a familiar status to a perceived dependent role, creating anxiety and a sense of hopelessness.

According to Lubkin (1990), when the physical ability changes, a psychological adjustment may occur. The emotional response to loss of mobility expresses itself as grieving, a process unique to each person, developing at an individual pace, that

must be understood as such. Behavioural responses may seem irrational and inappropriate to both client and health provider. In addition, somatic manifestations (pain, anger, loss of appetite, sleep disturbances and slowed thinking and action) may be symptoms of the grieving and adjustment process.

4/6 "You just think yourself as ill , you can see reduction in your bodily functions movement, health is deteriorating a gradual sort of slope down but mentally you don't accept the fact you were actually ill , because I wasn't bedridden or anything like that, I was mobile but very limited. It was frustrating that I couldn't do things that I could before, I've got a large garden and I couldn't handle anything in the garden because physically I was finished, I had no strength, I wasn't eating I lost my appetite or the drugs I was gave me nausea to the food".

According to Hanson and Gerber (1990), physical skills and capabilities comprise a major component of self-identity. In some cases, unique and special skills acquired as a result of native talent, special training, or persistent effort become bases for admiration from others as well as for personal pride and self-esteem. When the ability to engage in these skills is impaired as a result of a painful injury or disease, the result can be significant blow to one's self-worth. In addition, there are many common physical skills and activities that are taken for granted by most healthy people. Walking, running, jumping, bending, pushing, pulling, and lifting, for example, may be ordinary, everyday actions. Although they are not used as a basis for pride and self-respect, they become a part of one's identity. Little attention is given to these activities until some injury or disease makes it difficult or impossible to carry them out. When physical impairment from an injury or disease is long-term, one is forced to go through a process of adaptation and redefinition of one's basic self-identity.

6/8 "I can remember this is how you tend to feel after most operations, you are really constipated as well as that is a horrendous experience plus my legs were so weak I mean even I could hardly pull myself out a chair like this, my legs were so weak, I couldn't stand up I had to pull me up. Particularly a sofa or the settee, I couldn't get out of them, people had to pull me up. I think it was just the physical weakness after the operation, I think it was particularly in my case because I had been in bed for about 2 months beforehand and I was just very weak to start with.....I thing some of these times I feel my legs are still a bit weak but I get by.."

According to Lough, Lindsey, Shinn, & Scotts (1985), the most important determinant of the quality of life perceived by the patient after surgery is his or her health status. Quality of life is negatively associated with the number of physical symptoms present. Even patients who seem to be psychologically well-suited to transplantation tend to become unhappy or anxious if they develop complications. Family relationships, sexual function and leisure pursuits are compromised by the return of ill health. The feeling may be worse the second time around because of disappointment in and a loss of idealization of transplantation, the "miracle" that was supposed to magically solve all problems: "if only I can make it until my transplant, I know everything will work out all right".

As O'Brien (1985) states, long life is not the expectation of the heart transplant patient although all hope for it. Rather, it is the quality which gives life a richness not experienced since before their illness.

Changes in mobility that were visible, seemed to intensify feelings of stigma. The problems associated with fear of falling or losing balance in public were further

complicated by the need for assistance in certain situations; causing difficulty in accepting offers of help. Terms with negative connotations directed to patients, were found to stigmatize them.

According to Bailey and Clarke (1989), with respect to coping with social relationships, the major problem seems to be the attitudes of others who impose inappropriate stereotypes upon the disabled.

16/8 "I think it was just the physical weakness after the operation, ...I can remember eventually when I got home-one of the jobs I needed to do was to check the tyre pressure in my car on the driveway at home and I bent down put the foot pump on with the pressure gauge on opposite the tyre and I couldn't stand up again.. no strength in my upper legs....I had to shout for some of my family to come and lift me up onto my feet again ...they all thought I was crazy...that was a horrendous experience. I think there was one day even from the flats we went to get a taxi into Glasgow to go for some lunch and the taxi the black cabs you tend to walk into them bend down and I just fell into this thing and I couldn't even it took me all my time to get into the seat.....when I fell onto my knees the taxi driver thought I was drunk, so I think that was one of the worst experiences".

The physical weakness seemed to be a multiple problem, taking into consideration the restrictions caused in one's life, the effect on his/her self confidence , the negative effect on his/her image and on others' perception of him/her, (in the previous extract, the family thought he was crazy and the taxi driver that he was drunk)and consequently the psychological problems that might be raised.

The feeling of being disabled was traumatic for this patient (in the above extract). Also the importance of being independent was the main subject that he constantly mentioned. According to Shapiro (1990), illness for most people requires adaptation to a role with decreased autonomy and increased reliance on others, which creates a strain for patients. Awareness of one's dependency on others' help for tasks he once performed himself, as well as for health care, could be demoralizing. A sense of humiliation was often at this stage, with feelings of poor self-esteem and inadequacy leading to social isolation.

As Lubkin (1990) states, when mobility changes, dependency, depression and dissociation are common. Body image changes are common when mobility changes and self esteem is also affected. Disability frequently includes necessary dependence on relatives and professionals. The dependent person often over-reacts to perceived threats to self-image. According to Hanson and Gerber (1990) a common response to difficulties in accepting physical limits is chronic frustration and irritability. Patients who experience these feelings often appear angry and may present difficulties in getting along with other people. Each time they encounter a specific situation in which they are unable to perform an activity that they previously had done without effort, they become frustrated and irritated with themselves (as the patient in the above extract while he was trying to check the tyre pressure in his car).

Bandura (1977;1986;1989) emphasized the importance of perceived self-efficacy (our perception of our own ability to handle events) on everyday performance and behaviour change. He presented evidence suggesting that high perceived self-efficacy allows people to perform better than those with equal ability but less faith in their ability. Abraham and Shanley (1992) stated that each of us has our own everyday challenges. These give our lives structure and when we meet them successfully make

us more self-confident. It is only when we doubt our ability to cope that such challenges become stressful. In other words lowered perceived self-efficacy generates stress. Change and loss are therefore stressful to some extent for everyone because they require us to readjust, that is create new representations of ourselves and our world and to establish new relationships and routines.

Health care providers need to develop insight into problems created by loss of mobility. A better understanding of the psychological and sociological problems that arise with altered or impaired mobility can assist health care providers to help heart transplant recipients with appropriate interventions. As Lubkin (1990) states, since feelings of insecurity and worthlessness often surface when a person is coping with mobility alterations, the health professional should nurture the individual's self-confidence. A positive, realistic perception of abilities as well as limitations can support self-confidence. Focusing on physical limitations can become frustrating and overwhelming, yet it is part of the adjustment process. Positive support includes acknowledging that adjustment is hard work. Any intervention program of care should clearly address the psychosocial needs of clients with altered mobility and their significant others (Baum & Rothschild 1983), to make these needs more manageable and less overwhelming.

3.2.2. Problems of long-term medication.

This sub-category included a description of the problems due to the long term medication that heart transplant recipients had to follow as part of their treatment. These problems were either complications or side-effects of the medication and mainly of the long term steroid therapy.

Some of the patients who were interviewed, seemed to see medication-taking as part of their daily routine activities, like drinking and eating, and consequently did not report much difficulty in taking their medication correctly. However, distraction because of, for instance, intense activities, interruption of normal routine and having to take medication under unfamiliar conditions, were described by patients as inhibiting the accuracy of medication behaviour.

The medication schedule, the timing and frequency of medication intake, was stated as influencing medication behaviour. Big pills which were difficult to swallow and large amounts of drugs were viewed as inhibiting factors in taking medication. Unpleasant side-effects of medication were also seen as negatively influencing compliance with medication regime. Knowledge of the time, method of administration, dose and purpose of the medication were needed in more specific detail.

Patients often complained about the numbers of pills and the amount of drugs taken.

9/5 "Heart transplant- it was a marvelous thing what you can do- but it probably would be better if you could get the drugs bit sorted out-I think that's all".

24/2 "I get trying to reduce the steroids which I was on twelve and a half since I was discharged from hospital over three years ago ..I'm going for a scan today to see if they can reduce that further...I don't think there is anything other than that I say I keep reasonably well".

29/6 "You are a bit wary of all these drugs you are taking you want to get them down as low as possible- I dislike the taking of drugs because I have problems taking drugs anyway trying to swallow them....that's another problem you battle on you just take them."

2/6 "I take a lot of blood pressure drugs and anti-convulsant drugs and those drugs also affect the rejection drugs so I'm on very high dosages of everything which is a pest you know."

Some patients also saw the number of drugs and the problems caused by them as "bad treatment".

18/2 "I feel as if the medication I'm on is not right-they put me onto steroids for a week to see if it would boost me a wee bit- as far as I am concerned I've been on medication and that's didn't help me at all , I've got to be honest about it, the last two days have been just rubbish..sometimes you canny even speak...."

18/3 "At the moment I feel as if there's something just not right- you know they treated me something just not right- something's missing, something's wrong with the medication something just not right-too long..."

11/11 "It's an awful ordeal and the drug side of it is pretty bad and when you are on the drugs for life so its catch 22 you've got to keep taking the drugs or you die. I think the whole thing is still in its infancy eh surgically its probably as near as perfect as you can get but I think the drugs side leaves a lot to be desired and maybe in the future somebody will get the benefit of some research ".

Understanding all these problems that patients experienced due to the complicated regimen of medication was of great importance because of their role in affecting patients' compliance. And non-compliance with medication was understood to have an obvious bearing on the quality of life of transplant patients (as was described by patients in the above examples).

The post-surgical medical regime, in heart transplantation, is highly demanding in that the patient is required to self-administer multiple medications in specific dosages at appropriate intervals of the day; without proper administration of these medications, the patient will experience serious complications (Nussbaum & Goldstein, 1992).

Two types of non-compliance were found in this study: failure to comply with the prescribed follow-up visits to the outpatient clinics, and failure to take medications as directed.

25/1 "I found it extremely difficult, I'd been used to a lot of drugs beforehand and then they are changing the drugs and the drugs are different again so it was like being re-educated with another lot of new drugs. What is good is that the nurses work with you , with the drugs and they're educating you what they are for and why you are taking it and the side effects they can have and this is quite helpful, once you get used to taking them you think well this is for to help this and this is for to help that".

In a study from De Geest, Abraham, Gemoets, and Evers (1994), self-efficacy has been proposed as one of the major determinants of medication behaviour, defined as the perception that one can master a certain task or perform adequately in a given

situation (Bandura 1986). According to Bandura's Social Cognitive Theory, self-efficacy beliefs reflect people's thoughts about their capability to perform certain behaviours. These cognitions, in turn, influence the activities that individuals choose to approach, as well as their motivation and persistence in view of obstacles in performing those activities. Self-efficacy beliefs affect thought patterns and emotional responses to taxing situations (Bandura 1986; 1989).

Unfortunately, and of considerable concern to nursing practice, patients following a long-term medication regime tended towards non-compliance rather than toward compliance (Haynes, Taylor, & Sackett, 1978; Meichenbaum & Turk, 1987). Non-compliance can negatively influence the therapeutic outcome. According to Bandura (1982), compliance with prescribed medication regimes is influenced by the perceived beliefs of efficacy with medication taking. Thus, patients with strong self-efficacy beliefs about medication behaviour will be more motivated and will persist longer in correctly following the prescriptions. In contrast, patients with weak beliefs will show poor compliance.

Literature on compliance (Haynes et al 1978) suggests that when drug regimens are complex, non-compliance becomes more likely. In a study by Baumann, Young & Egan (1992) it was found that the high level of compliance with medications may be related to the perceived consequences of failing to take these drugs. Recipients frequently said they thought about skipping doses but never did so because the consequence would be rejection, soon followed by death. These findings are consistent with the Common Sense Model (Leventhal, Meyer, & Nerenz, 1980), which would predict that when the consequence of not engaging in a behaviour is too threatening, it may override barriers associated with adherence to a complex treatment regimen.

According to Shapiro (1990), non-compliance in heart transplant recipients has been viewed as passive suicide. The author suggests that evident non-compliance should spur inquiry into changes in the patient's level of understanding of the regime, complications and side-effects that may have been overlooked, problems in the relationship with supportive figures, and problems in the doctor-patient relationship. Shapiro also suggests that improved understanding and the associated sense of mastery increase self-esteem and improve compliance with the regimen.

Understanding, promoting and maintaining adherence to prescribed medication regimens are critical nursing interventions for patients with acute and chronic illness (Bulechek & McClosky, 1992). Especially among patients with chronic illness and/or requiring long-term medication, the consequences of inadequate or inappropriate medication behaviour can be significant (Rovelli et al 1989; Schweitzer et al 1990; Cramer & Mattson 1992; Kruse 1992).

According to Rogers (1984), immunosuppression following heart transplantation creates a significant number of complications and side effects for the recipient. Many of these symptoms are reported to cause considerable personal distress. It has been also suggested by Rogers (1984) that these complications negatively affect the recipient's quality of life. Many patients were found in this study to have experienced delirium, with the form of disorientation, concentration difficulties, memory loss, sleep problems, sensory loss, confusion and hallucinations.

Delirium is an acute organic mental syndrome -commonly recognized problem post-transplant- characterized by impairment of orientation and cognitive function, disturbance of day/night cycles, hallucinations, with fluctuation of the severity of the

syndrome over the course of the day (Diagnostic and Statistical Manual- American Psychiatric Association, 1987, pp. 101-103). Delirium by definition has an organic basis. Cardiac transplant recipients with past hepatic, renal, or cerebral dysfunction may be prone to postoperative delirium. Cyclosporine, uremia, hypoxia, narcotic analgesics, infections, the intensive care unit environment, and high doses of steroids (Ling et al, 1981) are postoperative factors that may contribute to the development of delirium. Other patients, although not delirious, may develop a psychotic illness in the intensive care unit, with paranoid delusions and hallucinations (Shapiro 1990). Delirium, as is also described as an postoperative organic brain syndrome, accompanied by psychosis in the first 48 hours after heart transplantation, is probably the result of intra-operative ischeamia; usually is being manifested with impairment of orientation (Hotson and Enzmann, 1988). "Postcardiotomy psychosis" describes a group of abnormal behavioural responses that have been found to occur during the immediate postoperative period in susceptible patients who had cardiac surgery. Initially described by Blachly and Strarr (1964), this phenomenon implies a syndrome that consists of impairment of orientation, memory, intellectual ability judgment, and emotional state or affect. Symptoms of postcardiotomy psychosis encompass a wide range of behaviours varying from confusion and disorientation to visual and auditory hallucinations, delusions and paranoia (Heller et al,1970; Lasater et al 1975; Kornfeld, 1965; Salder, 1979).

Disorientation:

6/3 "I fell asleep on the Monday afternoon and all I can remember is wakening up on the Wednesday but it was a horrendous experience because I thought it was still the Monday and I was calling them all liars under the world because they bring

the paper in and showed me a Wednesday's paper and after giving a lot of abuse you know for a wee while I think they got the hospital chaplain up to calm me down you know, and to convince me I was OK. ...I had been through a traumatic experience".

In this case the disorientation made the patient so upset -and he started also abusing people-that he needed somebody to calm him down. It is not only the disorientation itself that caused these upsetting feelings but also the fact that patients are so worried about their mental ability. The fact that they have undergone such a major operation and the heart such a main organ has been transplanted, caused them anxieties whether their personality and mental ability will be affected.

Concentration problems:

6/9 "I found my concentration was terrible and simple wee jobs that I used to do very easily like wiring something up wiring electrical plug and socket or putting connectors in a bit of wire I remember once doing something I was connecting up a Hi-Fi I made the same mistake about four times and I was so annoyed at myself I just threw the thing away I got quite frustrated ...and went back to it later you know....I used to do my concentration on working on fine things I think the drugs you are on tend to a wee bit shaky as well, not as steady as you are now you know much steadier now that I was in the early days- Its getting harder to remember all the time the fact that you are feeling OK. and its all behind you".

The problem with his concentration had already affected his self-confidence. He found it difficult to accept that he was not able to do things that he used to do, and

he had some difficulties in forgiving himself for making mistakes. The effect of these problems was such as he found it difficult to accept that it was all over, now he was fine, and all these belong to the past.

Memory loss:

23/2 " ..... due to the effect of the anesthetic had on my brain ....I was having great difficulty remembering what my drugs were for and things like that and I had great difficulty reading, doing crosswords...in fact the surgeon said to me you'd better just stop and this was worrying me a bit particularly when I couldn't sleep at night and that was the worrying bit I had ,but I remember one day I suddenly realized when I was reading the newspaper that things were going in I thought oh I've got them written in my notes...so I got out my booklet and memorized all my drugs and all the side effects and when the nurse came in for my nightly education as she called it she said right Cyclosporine, what's it for I said right away, she said give me two side effects I gave her them all and she looked up she said you've got it and I said yes I've got it , give me everything now and it was just suddenly that one day it was the anesthetic that was getting me...I thing that worried me more than anything you know even the operation .....I'd got over that I was all right....".

Sleep problems:

23/4 " .....the other problem is ....I think this is occurs for heart transplants only, not things like liver, kidney transplants but sometimes your body clock is turned upside down and I find I have to get up sometimes two or three times during the night to go to the toilet and I tend to fall asleep during the day particularly in the

afternoons and when I do fall asleep it's very deep sleep and nothing can wake me, telephone, doorbell.....but I'm not concerned about it my wife gets concerned about this, it is natural thing, but for example when I woke up this morning I woke up about 4 o'clock and normally I would get back to sleep again but having to come through here knowing that I had to get up again at 6 o'clock to get an early train I had great difficulty getting back to sleep, in fact I didn't I was just dosing so that's another side effect but it doesn't really worry me I don't mind whether I sleep during the day or at night its just one of these things ..not too concerned about the side effects I know they're going to be there so I just accept them".

No senses:

3/2 "I had no senses at all , hot and cold were just indifferent, I was sticking my tongue in boiling hot water coffee and I wasn't feeling it, and my tongue literally burned away, as well and then I would have a hell of a thirst I'm not surprised, it was probably to take away the heat in my tongue which was there but I didn't feel , no feeling at all, that was funny. Touch was the same-I know that I was touching something and then all of a sudden I would just stop and think that I didn't feel it".

Confusion:

3/2 "Everything was back to front I was reversed I would do something and then when I went to do the thing that I had said I was going to do I would do exactly the opposite. Well one example, they wanted my sugar level down before I become diabetic and then I would be standing there saying well but I was getting the sugar

this excess of sugar on my porridge and I'm like this complete opposite to what I was thinking, you know it was crazy. Everything was reversed. And I ate so much sugar that I became diabetic and really bad I became a high, high four treble four my sugar count and I was really close to die, and I said to the doctor I canny help it I'm doing the exact opposite to what I mean, I was so confused with this feeling and it was driving me nuts , it was really getting me down. They were telling me to do something and I was thinking I was doing it and I was doing the opposite and I was arguing with them, and we had this bloody argument and I got confused and I was frightened really, that was horrible feeling that was the worst thing that has ever happened to me . So they took off a drug one specific drug and that made all the difference, I just got better and better".

Hallucinations:

15/5 "Once I had quite a vivid experience, I woke up and I looked up at the clock and it was quarter past three and there was somebody standing at my side , and I remember trying to short of focus on who it was and I couldn't focus. And I said you know I was ill and I'm still very ill, and this voice said, no don't worry you are going to get over this, and I said am I going to die and they said oh no you've got a lot of damage to do yet no way you're going to die so I dropped off to sleep again. In the morning I asked the nurse who was at my side of my bed last night about quarter past three and she said nobody and I can assure you because at five past three we were all involved in an emergency that it was two cubicles down from yours and we checked in on you and your monitor and you were sleeping like a baby. And I was convinced then because of my faith that it was whatever you want to call it guardian angel, God standing at the side of my bed".

As Nussbaum and Goldstein (1992) state, the heart transplant patient demonstrates deficits in attention/concentration, learning and memory, concept formation and cognitive flexibility. The patient's cognitive status may affect his/her compliance with the medical regimen, increase the risk of medical complication, and reduce the capacity for independence.

Health care providers need to be able to recognize symptoms of delirium, as these symptoms can negatively influence compliance with medication regime.

Numerous investigations have been conducted to elucidate factors that contribute to the development of postcardiotomy psychosis. Such studies have historically examined the influence of three distinct categories of variables on the development of the psychosis, namely, physiologic factors, environmental factors, and psychological factors (Lasater et al, 1975). The purpose of these studies has typically been the development of appropriate preventive treatment modalities for vulnerable patients (Elberry, 1972).

In summary, research indicates that postcardiotomy psychosis may best be viewed as having a multivariant etiology encompassing psychological, physiologic, and environmental factors (Quinless et al 1985). Quinless and colleagues in their study (1985), examined the relationship between selected preoperative, intra-operative, and postoperative variables on the development of postcardiotomy psychosis in adult patients who had open heart surgery. The results indicate that the intra-operative variables of systolic blood pressure, perfusion, and anesthesia time are positively correlated with the development of postcardiotomy psychosis during the first and second days after surgery. The findings of this study are applicable to critical care

nurses in the processes of assessment, intervention, and future research studies. Intellectual awareness of the commonness of this phenomenon enhances the nurse's perceptual empathy and enables him/her to investigate "troubleshoot" possible factors affecting the development of psychotic behaviours. In addition, preoperative education should continue to focus on stressing the physiologic sensations and transient psychological sequelae common to cardiac surgery. It should be stressed to patients that depression is a common, anticipated emotional response (Quinless 1985).

Mood swings was reported by most patients as another side effect of the medication.

3/5 "I cried a lot under the steroids I would cry I would weep I was so bloody frustrated I would cry for no reason, I would feel very happy and then very sad and that wasn't nice because I don't cry easily but I was crying every two minutes , that was embarrassing, and then it got to the stage where I wasn't really bothered if I was going to cry or not, I was doing it deliberately but it became easier to cry than keep it, and that went up and down for a good few weeks".

Other medical complications reported in the study as result from chronic immunosuppression for the heart transplant recipient include infection and rejection.

Infections:

Infection is the primary cause of morbidity and mortality following cardiac transplantation (Vargo, et.al., 1989; Muirhead, 1989). As Vaska (1993) reports,

susceptibility to infection remains high in this population because of the lifelong immunosuppressive regimen patients must follow to prevent rejection of the transplanted organ. Cardiac transplant recipients are most likely to succumb to infections caused by cytomegalovirus, Epstein Barr virus and bacterial organisms, especially staphylococcus. Fungal, protozoal and herpes simplex infections are also frequently troublesome to the transplant recipient.

24/1 "I had problems up and down with infections , and of course I was just under 60 years old when I was done so all the rest of my organs are now 63 years old but I have a young heart and I think it's causing a wee bit problems ...and the lungs of course are pretty bad and I still have infections from time to time mainly infections...".

24/2 "I keep reasonably good health but if I get an infection they put me onto antibiotics, these always tend to pull me down and because of my condition they have to be careful but not to become immune to antibiotics because if I then take a serious infection they can't treat me. Eh viral infections are a wee bit different you know ,they could do something ...for a virus in my throat your herpes virus and I don't know where these things come from but they seem to float about the air".

24/9 "I had a lot of problems after my heart transplant, I had my heart transplant on the 17th February 1992 but I didn't get home until sometime in August because I took a lung infection and I lost an eye through it ..".

The problem with the infections was that brought a lot of worries to the patient. Patients did not like the effect of antibiotics (24/2:"*tend to pull me down")*, worried

about being immune to the antibiotics and also worried of how easy is to get an infection (feeling hopeless to protect themselves).

As Vaska (1993) states, critical care clinicians can control the incidence of infection in the cardiac transplant population by monitoring the patient for early signs of infection and instituting appropriate isolation techniques.

Rejections:

Rejection remains a major complication and an important cause of death after heart transplantation, despite improved immunosuppressive protocols (Kriett & Kaye, 1990). Despite immunosuppressive medications, recipients maintain a degree of immunocompetence and the ability to recognize and react to the transplanted heart (Dressler, 1993).

Patients in the study expressed their fears and concerns of rejection and the consequential complications.

18/1"After the heart transplant the problem is the rejection....they gave you a lot of medication that stopped your heart, your body rejecting your heart and unfortunately this develops into a lot of infections, you pick up infections, the average infections, the lungs, liver, brain and these other ones CMV..."

1/1 "I experience quite a bad time with rejection, they tried to control or tried to compact the rejection by means of medication tablet form which didn't really work, I was having too many high rejections too often"

The first rejection episode was considered as a sobering and worrisome event for the recipient and family. They acknowledged that they were told repeatedly that rejections are to be anticipated, and that the recipient is monitored closely for the first few months following discharge for rejection episodes.

7/6 "My biggest fear is the rejection, that would be the worst thing that could happen to me if I start reject, I can cope with anything else but the only fear that I've got really if the heart reject if it only started to reject and I won't be able to understand it, although they've assured me that it's not a problem but in my mind that is a problem".

Classical cardiac symptoms, such as angina or palpitations, are absent after transplantation because of the denervation of the transplanted heart. Without the ability to monitor familiar cardiac symptoms after the transplant, recipients face some degree of uncertainty about how to interpret bodily information to assess their health status (Baumann et al 1992).

Endocardial biopsy is a method to detect rejection. According to Baumann et al (1992) the procedure is relatively painless. Since there is no nerve supply to the transplanted heart, discomfort is confined to the site where the biopsy instrument is inserted into the right side of the neck. However, in some cases patients appear to be frightened with even the idea of having a biopsy.

6/13 "I haven't had a biopsy for over one and a half years now which cheers you up...I think the day they find some alternative to doing biopsies I think it will be a great thing you know I'm sure there is research going on somewhere to see if they can detect rejections without having to give you a biopsy....I'm sure there is... I

hope there is ...I'm sure somebody is working on it already its not all that bad, it's just one of these things....we all talk about it and you are sitting out in the clinic, and the horror story depends whose doing it today... and all the rest..he is terrible".

In this case what helped the patient was the hope that research is going on and there might be improvements in the way of doing biopsies.

29/3 "I've had quite a number of biopsies, two of them have been pretty horrendous....you know you get high before a biopsy your temperature and blood pressure just rockets so that's another problem but again you've got to accept it."

As Allender et al (1983) state, during the immediate post-surgical period, patients believe that they are no longer ill. They often think they are among the small group of patients who do not suffer a rejection episode. After experiencing years of coronary difficulty pre-operatively, this belief often leads them to a false sense of hope usually characterized by positive, even euphoric feelings. However, the post surgical period generally ends abruptly with the first medical complication, or first rejection episode. As they enter this stage of adjustment, they realize they are still sick and often become extremely despondent. Transplant patients realize that they have traded one form of illness for another-the previous cardiac symptoms of pain, breathing difficulty, and fatigue for the new problems of rejection and infection. The more euphoric they are during the immediate post-surgical period, the more despondent they may become as they realize they are still sick. As the rejection or infection resolves, their depression or despondency usually improves. Patients then realize that although they are still ill, their condition is controllable, thus initiating their slow, extended recovery prior to hospital discharge

14/6 "Well it was nice to get a new life again but I was a little bit disappointed you know for the first 3 weeks after it was really good, feeling good...I could walk maybe 2 miles or so, I could run up the stairs and back down which I couldn't do quite a while before it but then I took a virus what they call CMV virus and since then I've really went down hill- it was quite disappointed after that...I mean for the first month really good and then just deteriorating...".

According to Suszycki (1986) most heart recipients experience at least one rejection episode, forcing them to acknowledge that success is not guaranteed, that the struggle for health is far from over and that death is possible. Past feelings of uncertainty, fear and despondency revive.

Other complications post-operatively reported by recipients in this study were: Osteoporosis, vision disorders, back disorders, diabetes, epilepsy, hypertension and renal insufficiency.

14/6 "I've been in and out of here a few times different operations you know they took my gall bladder away I had a stomach operation, hernia....toe nails took off...this is all due to the drugs and my eyesight is going now due to the steroids I'll need to have a cataract operation now- so the next thing they're going to try is to take me off the steroids to see if that'll help my eyes....is quite a bad thing too because I used to have quite good eyesight but it's getting really quite bad now to read a paper ...get a haze coming over your eyes...if I get them sort of checked out I'd be quite happy because I think if you were blind it would be pretty bad you know if you couldn't see.... and it affects your hearing too I had bother with my ears too but got that sorted out just catch 22 ...one drug against the other..".

13/6 "I got diabetes and that affected my eyes, now some of the drugs are affecting my eyes, there is like a skin but I don't know the name.... I think it's due to the cyclosporine...and osteoporosis, and that gives me a wee bit of a problem, my bones get sore."

23/3 "The main things that affect me are the side effects of the drugs I get swollen ankles every day no matter what I do whether I'm standing or sitting and they just go away when I go to bed at night and I've got this puffed up neck and stomach because of the steroids. The main side effects I have are the swollen ankles, swollen feet and I have to be careful because one of the symptoms of rejection is swollen ankles but I think I can tell the difference as long as when I go to bed if the swelling has gone down by maybe two in the morning then I know everything's O.K.. but it no matter whether I am standing or sitting they get to swell eh I thing this is one of the reasons I just couldn't go back to my job as a lecturer ...this is one of the problems".

29/7 " ....and then the side effects of the drugs has left me with osteoporosis which was very bad at the beginning of the year and I was very low at that stage."

2/1 "The first 6 months were terrible, I had a series of setbacks, I was unconscious for 3 days, at one time I kept collapsing....I became epileptic-I had 3 grand mal seizures and the problem with coping with that was harder than the coping with the transplant.....I thought losing my driving license because epilepsy was traumatic affecting my confidence quite a bit for a long time, but I got it back and I bought a brand new car, I'm driving at 90 miles per hour again. I'm quite happy ...."

9/1 "I had osteoporosis the year before and fractured my spine twice and was admitted for 6 weeks and realized I couldn't play any more golf; I've had shingles in my head which is worse than the transplant".

In the last two examples patients explained how experiencing side-effects of the medication, or complications was worse than the heart transplant operation. As was found in this study the extent of suffering from these side-effects depends on the patients' perception about side effects having such a serious affect on them. Patients perceived these symptoms as being worse than the heart transplant operation. But what do they actually mean by "heart transplant" when differentiating it from the side effects? Heart transplant should not be seen separately from these side effects because these side effects, as part of the treatment, are part from what characterizes the heart transplant experience. One possible answer was that patients' perception here was influenced by their expectations. They were expecting the heart transplant as being "something" that would solve lots of problems as soon as they underwent the operation, something that eventually did not happen or it was not obvious.

According to Lough's findings (1987) the fact that heart transplant recipients perceive side effects as having a relatively small impact on current quality of life suggests that a process of adaptation to certain symptoms may occur. Adaptation to side effects and alteration of life-style or habits to increase personal control over side effects is a normal process (Strauss & Glaser 1975). The side effects do not disappear but individuals try to make them as "invisible" as possible by redesigning their life-style, watching for early signs and side effects of the impending crisis(such as infection or injection), and managing the crisis if it occurs.

3.2.3. Changing body image

Illness or injury usually involves a change in body structure and/or function which may be temporary or permanent. Roberts (1986) argues that this forces the individual into a body image change. Frequently more than one bodily change takes place at the same time, such as a change in appearance, a change in functional ability, a change in control over one's actions.

However heart transplant patients focused more on actual body alterations associated with transplantation. Even in the generally positive study by Lough et al (1985), in which 89% of patients rated their quality of life as favourable, 20% reported tremor, 25% reported changes in bodily appearance, and 30% reported changes in facial appearance, which disturbed them "quite a bit" or "extremely".

11/6 "I had a big problem with weight, weight gain after the operation, and its been a hard slog, its taken a year and a half to get the weight down so it was away up about 15 stones and I think I'm down about 12 stones craven, the steroids certainly makes you crave for food".

According to Shapiro (1990) over-eating and altered metabolism due to steroid drugs lead to pronounced, excessive weight gain in many patients. Cyclosporine causes hirsutism and gingival hyperplasia. Facial acne is commonplace. These side effects may be especially difficult for young women, but they bother most patients to some extent. Teasing and social rejection may promote depression, self-hate, and non-compliance.

13/4 "I'm putting on weight, I think its due to the medication, I think I've put something like about 4 stones -I've got to admit if I have an emotional problem that's it - yet I buy something and I wear and I wash it and I put it away and I go for it a week or a fortnight later and I find that doesn't fit and I've got bigger and bigger, my feet are swelling and I find that they went a size bigger in shoes just wearing floppy shoes....but that's nothing that's a small price to pay for being alive".

According to Bailey and Clarke (1989), self-image incorporates the body-image, and the latter is extremely important in relation to health and ill health. Change in body image, especially if significant in degree, will affect the patient and the way he/ she copes with the condition. In general a person's body as perceived and evaluated by themselves, plays an important role in the maintenance of a sense of self-esteem and security.

Emotions which are experienced as a result of a change in the body image include anxiety and depression, shame, hopelessness and fear (Norris,1970; Henker 1979; Roberts, 1989;). Since the body image is so basic to our identity any change in it is a threat. However, the subjective and objective meaning of a particular change to the individual concerned may increase the level of threat experienced.

As Goffman (1963) states, body image change may be associated with stigma, in which case the individual has additional psychological and social factors to contend with. Goffman states that stigma occurs when the reality of an individual's appearance and social identity is negatively different from what is expected. If stigma is obvious to others during interaction then the individual is said to be discredited.

The implication of stigma is that for some patients, adaptation to the change in body image does not end their problems. Stigma makes every subsequent social exchange with strangers a potent stressor which has to be managed. The stigmatized individual copes by attempting to control information about the stigma, choosing carefully those to whom he or she will disclose information (Bailey & Clarke 1989)

13/8 "I find sometimes other people look at you as though you're a bit of a freak, ...I just live in a tiny village and everybody knows everybody and you hear them saying that's the woman that got the new heart, in the supermarket you know, that's the woman and she doesn't look different, I don't know if they expect that you should look different like a bit of kind of a Frankenstien monster...some people are like that and other people are very nice and very understanding you've to cope with that...at the start I found that its taking me hours to get round the supermarket telling everybody and you get all the different reactions, maybe not in worlds but the look of horror on their face....I came home and I was totally mixed up, went out feeling quite confident and came home totally mixed up with all the different reactions but it was the other peoples reactions to me rather than my own reactions...but its a small village..now everybody knows, nobody talks to me anymore, I'm not a celebrity anymore...."

The patient, in the above example, was very concerned about her appearance and how others saw her, and she did not like to be stigmatized; now she enjoys the fact that she is not the centre of others' attention. Actually the identity of being a cardiac transplant patient and being treated as a celebrity, and always receiving attention from others, made her feel very uncomfortable, as she tried to explain her anger with her non-verbal behaviour during the interview.

According to Abraham and Shanley (1992), as well as forming representations of one's self and others , a person also tries to understand others' representations of himself or herself. In order to become a fully functioning person one must be able to monitor his/her own behaviour and reflect on what others think of it (Henry and Tuxill, 1987). As soon as people are able to anticipate others' impressions of them, they begin to modify their behaviour in order to influence these impressions. This is known as *"impression management"* and it shapes much of one's everyday interaction (Tedesci, 1981). Snyder (1979) distinguishes between "high" and "low" self monitors, where 'high self' monitors are people who are especially concerned with their impression management and more likely to change their behaviour as they move from one social situation to another. However, even 'low self' monitors must pay attention to the impression they make. They must, as Goffman (1955) puts it, work at maintaining positive social value or "face". Harre (1979) has emphasized these "expressive" aspects of everyday life and argued that the avoidance of others' contempt and the gaining of their respect is a fundamental principle guiding much of human behaviour (Abraham & Shanley, 1992).

For the heart transplant patient, the "impression management" might be a more difficult task than for other people, taking into consideration that the changed body image may have already an effect on others' representations of these patients. It seems that there is a strong need for heart transplant patients to modify their behaviour in order to influence others' impressions of them as being invalid.

Self-image and feelings of competency early post-transplantation have been proposed to play in patients' ability to adapt to and psychologically incorporate the fact that they have received a new organ (Simmons et al 1987).

Body image change is of particular concern to health professionals who can offer support and information and change patients' distorted perceptions. Health professionals can offer reassurance to heart transplant patients that the changes in body image (for example, weight gain and swollen face) are only temporarily changes, and help patients to accept the changes and re-define themselves in positive terms.

As Zumbrunnen (1989) stated, in the post-transplantation phase, two opposed attitudes are required from the patient: he has to be highly compliant with strict medical prescriptions, including follow-up visits, cardiac biopsies and immunosuppressive medication; at the same time, he is asked to gain or regain capacity to be autonomous and to secure an effective self-monitoring and self-control, in order to manage himself his internist behaviour.

In summing, complications from the side effects of the use of chronic immunosuppression to prevent rejection have been recognized as problematic to the long-term heart transplant recipient. It has been suggested that these complications negatively affect the recipients' quality of life (Rogers, 1984). There is a lack of data on heart transplant recipients' perception of their quality of life and their satisfaction with that level of quality. In addition, it is not known whether there is a relationship between the frequency of symptoms associated with immunosuppression and recipients' perceived quality of life and satisfaction with it. It would be of value to know which symptoms are the more distressing for recipients. This information could be used in teaching and in preparing them for alterations in their post-transplant level of health.

Health care providers can assist these patients who have unrealistic expectations of the outcome of the heart transplantation. They can assist these patients in developing more appropriate expectations through interventions such as teaching about the disease process and the appropriate expectations after surgery. As Packa (1989) states, nurses can also assist patients who have inadequate information about future expectations by developing appropriate goals and interventions that will lessen anxiety and promote recovery.

3.3. I had to give up working

Many heart transplant patients had a job waiting for them and there was a gradual return to their former life. For others the transition was less easy and unfortunately a return to good health did not always herald a return to work. The inability to find employment causes bitterness and resentment (O'Brien 1985).

For some patients in this study who exhibited a low level of recovery, and early retirement was a necessity, they found unemployment as a big problem. As for some other patients the opportunity for early retirement was a more satisfactory alternative than continued job seeking.

14/4 "I still have a lot of breathlessness walking and that but other than that I'd love to be working again this is my biggest problem I had to give up work it was a big part of my life you know... I don't work at all and that's why I had actually to take early retirement because of my ill health "

By giving up work some other problems arose. People found it difficult to accept that they had lost a big part of their lives, something that they were used to for years, a habit a routine, something that used to keep themselves occupied. So now they tried to find an alternative just to take up their time. It became more difficult when it was not their choice but something that they had to do because of their ill health.

35/12 "As I said everything worked out fine for me and I've got no problems apart from lack of money at the moment because people just don't seem to want to take you back to work. Every time you try to get a job they say oh no no no chance , so they are not interested , the way the situation is at the moment people there's that many people looking for work that medically are 100% fit so they are taking these people first".

"I was off from my work for my Christmas holidays and I've never been back again...once I was off my work for 7 months, the company doctor saw me and eventually offered my early retirement through long term ill health .....and I was actually retired and I was lying in my bed feeling pretty miserable because when you retire you finish up your work with your pals to the pub for a quick drink, at least at lunch time, and here's me lying in bed....".

According to Fitzpatrick et al (1984) the effects of unemployment are not restricted to economic factors. Not having a place of work reduces the likelihood of meeting people and thus being able to establish social contacts and friendships. In addition unemployment carries a stigma in its own right. Thus the disabled may be doubly penalized by the stigma of disability and unemployment. This stigma is likely to produce feelings of isolation and depression.

But for some patients giving up work did not always bring problems. Sometimes it could be seen in a positive way, especially when it did not involve financial difficulties, and patient saw the new situation as beneficial making them less stressed and allowing more time available for the family.

17/2 "Financially we are OK because my wife works , she's got a well paid job, and it was the past couple of years that I had to really stop working....I think its been beneficial in a lot of ways, I've got a son he's 7 years old so he's seen a lot more of me than most kids see of their dad, we've had a great relationship-as a family I think we've been closer because of this simply through the fact that my son and I have grown up together I mean I was changing his nappies and all this kind of stuff, I was doing the mother role when my wife was working you know. We've definitely got a closer bond the whole family now the three of us ....I don't have the pressures of work I don't have the pressures of having to work late or having to go in on a Sunday or having to work weekends or anything like that I'm at home , there is no pressure again its been terrific. It opened up a whole new world for me and I'm starting to write again, I love writing and I'm writing a book".

2/8 "I have no financial worries, I thing that's a big thing it means its much easier for me to cope and because I don't worry about money. I had a big insurance policy that its going to pay out until I'm 65 so that means I don't need to worry about money and I think that's a big help. I had to resign from my job obviously a year after the operation but I had the insurance company is paying my wages now and I have enough money to travel whenever I want and to relax and to pay my mortgage, and that takes a lot of the strain off I don't need to worry about money but if I hadn't something like that I would have been worried about every penny".

16/13 "I don't work and that's because of my age and my medical history, they won't employ me its that simple as that, I used to work for the Post Office and when I had my transplant I was 55, I mean was no chance of me being taken back in again because of my age of course. And other companies that you write and ask for employment they sort of look at you and say oh 57 years old and had a major heart surgery there's no way , too many young people looking for jobs .... I mean there is not only the medical reason why I can't work but its social reasons as well, people are just not prepared to take the chance, and its a policy where they're pensioning people off just at 52 now and they are asking people to take early retirement."

Some patients found compensation for not working by doing voluntary work or helping others.

15/11 "I want to spent my time going to George Square in Glasgow and hand out donor cards to people and talking to people because people don't understand and they don't carry donor cards, they say I'm not going to die why I want to carry a donor card I'm only 25 years old but they don't accept the fact that they could die tomorrow through no fault of their own just pure accident and its all wasted. And I want to tell them about the importance of living life today and carrying donor cards so if anything does happen then at least their donors will be used for someone else".

16/16 "We set a sort of craft stall locally and we sell models and the money we make goes to the cardiac unit at the Hospital , the coronary care unit where I spent months before my transplant and we give them money for the patients' fund up, we've raised money for them by selling models.....we're currently doing something in 3 weeks time , we're doing something ... which is something immediate call out for accidents, a paramedic team, a sort of local doctors and if there is a major

accident they get called and its sort of initial medical aid but its all voluntary, and we're trying to raise funds to buy a wee sort of paramedic type ambulance and get some equipment. That keeps me going it gives me an interest it hopefully makes life a wee bit easier for some people".

Some patients seemed to try to find reasons for not returning to work.

38/13 "If I go back to work I might feel better, because I feel I'm too young to give up workout if there was the slightest doubt that it was going to do any harm it wouldn't bother me saying I'm not going back to work because in that sense live is too short , and if any job is going to affect your health to any there's nae jobs worth it now".

31/4 "My job before my transplant was very very stressful and I certainly won't be doing that anymore, I didn't like it and I found it not very lucrative ".

As found in the literature (Hanson & Gerber, 1990; p:110), for some patients, a chronic health condition can serve as a convenient "self-handicapping" strategy to excuse them for failing to meet their own vocational aspirations or living up to the expectations of significant others. They can then say to themselves or others, "I could have been a success.....if it hadn't been for my pain condition (injury, disease, surgery)". This face-saving device can enable patients to avoid facing insecurities regarding their skills, failure to meet their achievement goals, or unrealistic self-expectations and standards of success. Some also use pain as an excuse to avoid returning to a previously held job that was considered boring and unrewarding or overly stressful and demanding. As the authors argue, these underlying reasons for failing to make honest efforts to return to work can be discovered and tactfully

pointed out to patients during the course of individual counseling or in group therapy.

As Hanson and Gerber (1990) state, return to work has frequently been used as an index of recovery from illness. Return to gainful employment may be inappropriate goal for some patients with significant physical limitations. Although such limitations can interfere with many types of work, it is possible for some with even severe physical disabilities to become employed after being trained to use various types of adaptive equipment. Other factors that contribute to poor potential for return to work include unstable employment history before onset of the health problem, limited work skills, low aptitude for vocational training, and lengthy periods of unemployment prior to or following the disability. Irrespective of the reason, those who are either inappropriate candidates for vocational retraining or unlikely to return to work can be encouraged to find alternative work-like activities that will not only occupy their attention but will also enable them to feel useful and productive. Many may discover rewards in volunteer activities including work with the physically ill, disabled, elderly, economically disadvantaged or youth groups. Some potential reasons for a reluctance to return to work are less likely to be openly admitted or even consciously recognized.

3.4. Family support: giving and getting problems

This category included patients' opinion about the importance of the support they receive from family, complaints about not getting any support or sometimes getting even bad support, and about their new role inside the family. Patients also were

concerned about the strain that family experience before and after the heart transplantation.

3.4.1. Support: Good and bad

There is little doubt that family relationships continue to be affected by the chronicity of illness; however, reports are mixed as to whether the direction of impact is negative or positive. Some researchers have described an increase in family stress and marital difficulties after transplantation (Allender, et al, 1983; McAleer, et al, 1985) whereas others have detailed an improvement in home and professional relationships reported by heart transplant recipients (Lough, et al, 1985; Wallwork & Caine, 1985).

Good support: This represented patients' perception of the importance of getting support from their family and patients explained the role of support in helping them cope with the heart transplant experience.

1/2 "During this time you have various problems, you get depression sometimes, you have moods, many times lose your temper but it's only with the help of your family, people close to you that can come and help you there, and that happened to me and really helped, so although I'm still on quite a heavy number of tablets these problems have gone".

1/14 "One thing that you've got to get is support from your wife , your family, and at that time you take that as being a natural thing to expect but I would honestly say having been through it, I don't think you could do it on your own. My

wife was really more part of me than what she ever was and I think that's important. I think you really got to be honest with yourself and say well, if you had to be on your own and to have cope with all the phone calls, visitation to the clinics and the disappointments and all the rest of it... I think I would have given up , I think you need somebody who can give you a wee bit or well fairly big inspiration and the will to go through with it , and I think at the end of the day that's got to be a big factor in your success".

Many studies suggest that maintenance of a person's well-being may be strongly influenced by the social support that person receives. Morgan, Calnan, and Manning (1986:p. 261) concluded that: "a strong confiding relationship may be of particular importance in protecting people from depression following a severe life event, whereas other forms of social support may be of considerable importance on a longer-term basis." It seems as if reliable close relationships act as a buffer against the stress experienced when people are confronted with threatening life events (Cohen and Hoberman, 1983). Oatley (1988) points out that many of these threatening life events involve loss of a major role or social identity and so deprive people of an important aspect of their self-representation. Oatley also argues that depression results when the person is unable to identify an alternative role in which they can reconstruct their sense of self-worth. Thus the protective power of close relationships may be that they enable people to appreciate that others value them and to experiment with new ways of thinking about themselves after losing important everyday elements of their "self".

29/6 "I thought at one point that I 'd had enough I was just going to give up but with the support of the staff and more particularly my wife I came through it and anytime I got too down again they pushed me to keep me going."

4/3 "The families always been supportive, I've always been where I should be you know the head of the family..."

From this statement it became apparent that it was very important for the patient to keep his first role as a head of the family. By being allowed by the family to keep this role he understood it as good support. In some cases it was difficult to assess a family's supportiveness because of the patients' unrealistic expectations and the meaning given to support.

According to Abraham and Shanley (1992), social roles consist of shared rules or expectations which shape our behaviour towards particular others. We learn how to fit into these roles by attending to others' expectations (Goffman, 1961). As we move from one situation to another we may occupy different roles. In each role we have to take account of the expectations of role set members who we regard as having the right to define part of our role and who have differing sanctions in relation to our position within that role. In each role we are concerned to maintain our reputation as competent and to defend whatever acceptance and recognition we have gained. The demands of these roles compete for our time and energy, leading to *role conflict.* A typical source of such role conflict is between obligations of family members and to those at work. When we find it difficult to simultaneously correspond to the expectations of important role set-members across two or more roles we may become anxious about potential loss of reputation. This can lead to stress, loss of self-esteem and reduced coping. And when we can not change the established role relationships in operation we may succumb, we suffer from a loss of self efficacy and learned helplessness which leads to impaired psychological functioning and reduced coping. The opposite of improved health.

As Abraham and Shanley (1992) state, the kind of social support most helpful to patients may depend upon their health problem and their role relationship with others. In studying cancer patients, for example, Dunkell-Schetter (1982) found that informational and emotional support was seen as most helpful. In patients undergoing radiation therapy more than 80% of the sample regretted that they were not provided with sufficient information and the opportunity to discuss the situation more fully. Role relationships may also be crucial. Advice from a doctor may be viewed as very helpful even when the same advice is seen as unhelpful when offered by relatives or friends.

Accordingly, in a study from Rogers (1989), spousal behaviours that patients identified as supportive were reminders about infection control, accompanying the patient to appointments and exercise, dispensing as well as encouraging the patient to take medications, and preparing and monitoring the patient's diet.

Bad support: Represented patients perception about the consequences of not getting any support from family or sometimes even getting bad support.

Despite the evident importance of social support people who fall ill may actually receive less support from family members and friends (Wortman and Conway, 1985). In a study of breast cancer patients, 75% reported that they were treated differently by members of their social network. Of these, over half stated they were avoided or feared and almost three quarters felt they were misunderstood by others (Peters-Golden, 1982). Similarly, O'Brien (1980) found that hemodialysis patients' feelings of social alienation and estranges increased over time.

Potential helpers' misunderstandings of others' needs may result in unhelpful responses. Helpers may, for example, believe that they should remain cheerful and optimistic in their dealings with the ill person (Dunkell-Schetter and Wortman, 1982). However, if they feel they cannot live up to this expectation they may shun open discussion of illness and feel uncomfortable in interaction with the sufferer. This may lead to various forms of withdrawal. The ill person is likely to perceive this as rejection, and instead of the social network providing support at a time of crisis, the behaviour of its members may become an additional source of stress (Wortman and Conway, 1985).

As it was found in this study, and is clearly shown in the following extract, family members' ignorance or misunderstanding of the importance of the heart transplantation, was upsetting for the patient.

3/8 "I was very upset and disappointed with my family, after the operation they really didn't know what was happening I think half of them thought I was in for a brain transplant you know like they would come in after the transplant and talk to me as if I was a ...how are you getting on and I'd say I'm fine thank you -Do you feel all right? I'd say yes I'm fine I'd say for God sake will you stop bloody talking and they'd go Oh! you talk, I says well what the hell do you think I'm in for its a bloody heart transplant not a brain transplant. This is my family because I've got three sisters and a brother and we all fight like cat and dog so it took them a while to sort of realize what I was saying and then the doctor told them and the nurse told them and again they start oh you'll be fine in a couple of weeks and I says no I'll no be bloody fine in a couple of weeks, and my mum telling me oh you'll be fine , you'll be all right once you get home . We are from Polish, German , Irish, Scottish and its got all the bad wee bits of every family moulded into one , its like your Irish

family or your Jewish family that you see in the television they're all round the table , they're all arguing nobody could speak everybody kept butting in, everybody is talking and nobody actually hear, that's my family. But I started becoming intolerant because I would say one thing and none of them would listen because they're trying to get their own bit".

Family relationships can also be unhelpful and even damage the mental health of family members (Abraham and Shanley, 1992). Critical psychiatrists such as Cooper (1967) and Laing (1967) have portrayed the family as inhibiting individual independence and self-expression. It has been suggested that the apparently bizarre and meaningless aspects of schizophrenic behaviour is an understandable response to the oppressive environment of the family (Laing, 1959; Laing and Esterson, 1970). The management of family relationships is therefore likely to have a crucial impact on the success of rehabilitation programmes in which patients return to their families (Abraham and Shanley, 1992).

The offer of providing help, as it was shown in the following extract, when it took the form of overprotection could cause opposite affect than what it was meant to.

11/8 "I've got an old mother, that needs a bit of care and I find that I worry more about her than myself, and I think half her trouble is because she worries about me. She actually come into the house to look after me and I had to chase her away because she was only making matters worse for me, she was getting in the road setting pots on fire and my cooker was different from hers and my central heating was different and I was crabby really , easily upset , the slightest thing triggered me off. My mother always seemed to be getting under my feet and I had to politely tell her to get away back to her own house and I would cope better on my own, because

she was making problems for me that I could do without, and I found that I managed well".

Social support may be positive or negative factor, although not always- it is considered negative if it takes the form of overprotection (Larsson et al 1994).

In summing, as stated by Abraham and Shanley (1992), the size, density and supportiveness of our social networks can have important implications for our physical and psychological well-being. The interpersonal support the knowledge that we have potentially helpful relationships can enhance our self-concept. Such relationships seem to act as a buffer, protecting us from the worst effects of threatening life events. On the other hand, misunderstandings and self-protective attributions may inhibit relationship development and helping during illness, resulting in withdrawal and loss of social support. Relationships can also be unhelpful when they discourage help-seeking or compliance. Nurses can actively and systematically assess patients' social support; they can intervene directly to enhance patients' social support by developing caring nurse-patient relationships and indirectly by encouraging patients to seek and maintain supportive relationships with others.

As was found in the study, a number of heart transplant patients have got divorced during this period of transplant. Patients try to give their own explanations about the divorce, either blaming the partner for being careless , or trying to understand that partners couldn't cope with this difficult experience and they preferred to stay away from this traumatic event. But what is more important is that patients stayed alone, without having any support, to face and cope with all these problems that heart transplant brought, in a very difficult and demanding period of their lives.

Sometimes the marital and family problems that patients experienced post transplantation, were exacerbation of previous difficulties that have simply became more acute due to the additional stress of the transplant patient's convalescence.

11/4 "I blame her (his wife) for the whole thing, I had very bad support. I've had stressful work in the past, I was an electrical foreman in a huge car plant it was a very stressful job, I was basically just a stressful person uptight all the time worried, worried about my family, making money, keeping them happy, and I think I maybe put too much into my job and neglected my wife a wee bit, anyway she strayed a wee bit and that only added to my problems and subsequently I ended up in here".(he is divorced).

It was found in the literature that families that are disorganized before the onset of a crisis will experience severe disruption as a result of the subsequent stress (Lipman-Blumen 1973; Waller and Hill 1966). Family functioning prior to a crisis should therefore provide a measure of predictability on how effectively the family will be able to cope with the ensuing stress, and give an indication of their vulnerability to permanent disruption (Fife 1985). As Fife also found, families that have maintained adequate and functional relationships prior to a crisis will return to a stage of functional stability following resolution of the crisis, while the probability is high that families that were unstable before a crisis will experience increased disruption.

11/3 "I had other problems where my wife had left me some months before the operation, just kind of fell apart due to the stress of the whole waiting for the operation and I had to go through this all myself on my own and this only added to the problems I got. There were people told me I couldn't do it but I deliberately just

stuck to my guns and proved them all wrong when I got out of here I was virtually just looking after myself and I managed".

Shapiro (1990) found that, usually the feelings of resentment in the family members of the chronically-ill person, who are forced to adopt new roles and to relinquish many of their expectations of the ill person, are suppressed, at least for the short term. They may disappear at recovery. Sometimes, though, recovery is the occasion for a release of pent-up feelings of anger, and a previously stable-appearing family falls apart. Spouses may report that they feel obligated not to leave when the patient is ill; with recovery, this obligation no longer applies. For patients whose motivation for transplantation includes making it up to the family for all the suffering the illness has brought on, this is a frustrating and paradoxical development that vitiates the reward of renewed health. Conversely, patients who were resigned to a bad marriage when ill, may feel ready to leave the marriage when their health improves.

10/1 "Problems eh yes lots of problems my girlfriend had left me well we were just living together and she left me three weeks before the operation. She couldn't cope you know she couldn't cope with my illness and I didn't know anything about it, it was the first week after the operation I found she had left me so it was quite emotional I felt it was Oh...!! I couldn't cope I just couldn't cope. She's from England and the bigger anxiety for me was my son if she was going to go back down to England and not seeing him.....It was an anxiety-Occupying my mind, I couldn't concentrate to read I couldn't sleep, I actually never slept for about 2 weeks after the operation.....I never had any problems with the heart transplant, I never felt anything, it wasn't any discomfort....I never really worried about the transplant I was more worried about my relationship that it had gone up in the air

you know. I was more down than up you know with J. leaving and I still feel quite hurt that she left.....That was the biggest upset that I ever had and I got depressed. We're still friends but I don't know if I could trust her now anyway.....

The literature suggests a specific aetiological relationship between recent life events involving personal loss (e.g. loss of important relationships with others through divorce, death, etc.) and subsequent depression (Paykel et al 1969; Brown & Harris, 1978; Finlay-Jones & Brown, 1981; Dew et al 1992). There is a potential for deleterious mental health effects when multiple stressors-here, transplantation plus additional major life events- co-occur during a limited time period.

Nursing plays a vital role in the assessment, cultivation, and evolution of spousal supportive behaviours. As Abraham and Shanley (1992) state, by understanding the structure of patient's social networks nurses may be able to maximize health-inducing social support and minimize the detrimental effects of patients' relationships. Such understanding must be based upon an assessment of the patients' social network, the social support she typically receives and the level of demand and stress experienced in her everyday life. Nurses may regularly conduct informal assessments of this kind by observing the patient's interaction with family and friends over a period of time. This exploration of the patient's social network may heighten her awareness of those she could approach for help which may in itself have beneficial effects. Cohen and Syme (1985) suggest that such awareness of sources of help is a very important factor in how well people cope with stressful events. Assessing the nature of the person's social network will also help the nurse identify patients whose health may be "at risk" due to a lack of social support and may indicate whether the patient is likely to comply with advice and treatment.

3.4.2. Family takes all the strain

This sub-category included recipients' concerns about putting strain to the family.

A crisis event may be defined as one that threatens to disrupt the family, requires responses that necessitate the mobilization of previously untapped resources in psychological competence and social skills and demands that new role transactions be developed either temporarily or permanently (Adams and Lindemann 1974). Mechanic (1974) reported that family member's perceptions of the situation confronting them, along with management strategies they choose, have a crucial impact on the process of resolving the crises. New patterns of behaviour may represent efforts to protect the person from the impact of the stress, or these patterns may represent efforts to cope with a novel and complex situation.

4/8 "I know my wife and family did go through a strain.....so you realize after it, at the time you are not concerned because you are too ill but then you realized the what your family must have went through.....I feel grateful for the strength that they have shown.

As Artinian (1989) reported, despite the knowledge that illness is stressful for family members and family members have an impact on the health state of the patient, the stress that cardiac surgery places on families is of concern because of its impact on the health of the family members.

5/5 "Oh the strain was terrible....it's a harming disease because you don't get out so you are with your family all the time and they are watching you all the time and see the changes, these are the people that witnessed and watched it and took the strain, there's no outsiders or anything else taking the strain because they don't see

you its your family that take the strain all the time, I've noticed the strain lifted since the operation ..."

14/2 "See I've got quite a bit of heart trouble in my family, I've got a younger brother who had a bypass, my brother-in-low had a bypass operation and the family were quite concerned when I got it done, they were upright they were all annoyed- once I come through it they've been quite good really but they still worry every time I come in for a check up and they want to know what happens when I come back".

6/12 "I think it's very stressful for the family but I don't think you realize the strain they're under until you are in the position of having somebody else in the family going in for an operation as my wife has been quite recently.....you just start to realize the strain that must have been on them when you were in ,especially even more so with the heart transplant because you've got to wait for a donor to turn up with the right heart....it's quite traumatic experience for the family because they just don't know the length of time it will be, they've got to wait and if they see you deteriorating all the time it must be a horrendous for them....for other operations it's just the availability of the surgeon and the hospital facility but there's one major item that to be considered with the transplantation, if a donor heart doesn't turn up there's nothing anyone else can do for you and just keep on the medication adjusting the medication you are on".

14/3 "I was really worried about my wife how she would cope if anything happened to me, this was always in the back of my mind but we had a talk about it and she says she would just need to get on with it , she's quite a bit younger than me 15 years younger and all my families grown up and married now so she was always in my mind".

Patients often experience feelings of guilt for the strain they put on the family. As stated by Larson et.al (1994) the guilty feelings are often manifested in the patient's wish to reimburse the spouse for years of "suffering".

7/6 "I definitely put a hell of a strain on the family but I don't think it would be as much strain in the family as if I had snuffed it, I think that would have been a bigger strain if I died without this transplant, it would have been a far bigger strain on the family than going through the transplant and hopefully I'll get a good 2 or 3 years ken to make up for the strain they're going through the now".

6/12 "I think the family was under a lot of stress , there's no question about it and I was really sorry that it ever happened to them, but now that it's all over and they've survived and coped with it ,you are just that thankful you were there and able to cope with it , I'm quite sure some families they can't cope with it they just can't survive and sometimes families in that case break up ,but I've been very fortunate that we're all together and surviving still".

Patients often worried about the family for not getting the appropriate care and attention from the medical staff.

15/3 "If I was totally honest the staff are not as helpful as I would have liked them to be, I can't complain from the patient point of view but from the next of kin point of view, I wouldn't go as far as to say cold but not quite as co-operative , because as I say I think the next of kin go through as much of a trauma as the patient and the patient is in the hospital who are being treated by a doctor there are nurses coming in and out and the patient knows how he's feeling. But the next of kin doesn't know, the next of kin are sitting at home or doing a job worrying all the

time , waiting and everytime the phone rings they think what's wrong now and they have a really difficult time, I think its sometimes harder for the next of kin than it is for the patient actually. To be really critical that's not fair because the staff do a wonderful job with the patients and they don't have time to spend with the next of kin who sometimes can be seen as an unnecessary evil".

Gilliss (1984) found that spouses had more subjective stress than did the patients. She also found that families experienced several stressors in relation to cardiac surgery, that is, waiting for surgery, lack of control of hospital events, lack of privacy, feeling uninformed, and receiving misinformation from well-meaning friends.

3.4.3. My new role in the family(role transition)

This sub-category included patients' concerns of the role transition in the family that happens because of their health condition during the postoperative period.

After the joy of returning home and rediscovering the pleasures of undertaking domestic tasks often previously denied to them, there are adjustments to make. Reversed roles adopted because of the patient's illness may no longer fit (O'Brien 1985).

As Shapiro (1990) states, most cardiac transplant patients report improvement in their relationships as a consequence of their improved health after transplantation. As Shapiro continues, illness for most people requires adaptation to a role with decreased autonomy and decreased ability to care for others. Reliance on others

increases. This creates a strain on patients and families that is weathered more or less easily depending on a number of factors; in the case of heart transplantation, most families experience easing of the strain as the patient recovers. These results are consistent with Parson's (1951) definition of "sick role" behaviour that adopted by patients. Parson proposed that those people defined as sick (usually by a doctor) have two special rights, exemption from other social-role responsibilities and exemption from responsibility for the illness itself (Abraham and Shanley, 1992).

According to O'Brien's (1985) study, profound social changes seldom occur in the patient's life which affects the whole family, such as the inability to work, the loss of earnings, the loss of status and a reversal of roles whereby the patient is no longer the bread winner, a responsibility often taken by the partner. Or, where the patient is a woman, the husband may have to give up his job to look after children and home. The descent into dependence upon the ability of the partner, who for years may have been the supported one, to become the earner, or upon state aid is in marked contrast to normal life, with its future plans and aspirations. A sense of humiliation is often felt at this stage of dependency, with feelings of poor self esteem and inadequacy leading to social isolation.

6/11 "It's quite a traumatic experience if you are in the habit of driving around and you are not allowed to drive and you are relying on the family and friends to drive you around because you are not able to drive yourself and it's quite a feeling you know...on the way back when you are getting your license back again and you are able to drive that's quite a feeling of relief and you are independent, getting your independence back again, it must be rally quite a traumatic experience for people that are crippled or permanently disabled that they're having to rely on other people because in the early days after the op. you were relying on other

people very much for a lot of things and a lot of help.... the very first time I had to get a bath, it was the ward sister took me round in a wheelchair, used that kind of lifting device lifting me up and lowered me into the bath because I couldn't have stepped into the bath...they put me into the bath they got me sorted out I used to sit on the back and I used to slide into the water and there is no way I could get out of the bath myself for a wee while and when it's time to get out the bath two of them used to come and get me under the arms..it took a bit of getting used to..you know, two nurses dragging you out of the bath.....It's been a traumatic experience really altogether".

Awareness of his dependency on his wife and/ or nurses for tasks he once performed himself, as well as for health care, could be demoralizing.

35/3 "When I went home they were very supportive and very helpful but they do tend to spoil you, you know if you are sitting there they go and make a cup of tea or coffee and bring it to you and they will say no no just sit there , you know which you don't really need because you really need to do things for yourself otherwise you can end up just being sitting there and get family running after you all the time which I don't want anyway".

In this case the patient did not welcome his new role in the family as he believed that he was spoilt with all this special treatments. A need for independence, as the willingness to be active and do things on his own seemed to be important for him.

Transitions from the sick/patient and caretaker roles, for heart transplant recipients, may begin post-operatively in the hospital. Stresses of role redefinition

and of disruption of illness-centred family equilibrium may sharpen after the return home (Rauch , et al, 1989).

Coping may require lowered expectations and changed goals. The result may be depression, feelings of inadequacy and damaged self-concept. As Rogers (1984) notes, heart transplant recipients' struggle to live may be won, but the struggle to live well and fully continues. The struggle involves guiltless acceptance of the gift of life and the reconstruction of an intact, valued, optimally functioning self.

But changing roles in the family could be seen as beneficial.

17/2 "Financially we are OK because my wife works , she's got a well paid job, and it was the past couple of years that I had to really stop working....I think its been beneficial in a lot of ways, I've got a son he's 7 years old so he's seen a lot more of me than most kids see of their dad, we've had a great relationship-as a family I think we've been closer because of this simply through the fact that my son and I have grown up together I mean I was changing his nappies and all this kind of stuff, I was doing the mother role when my wife was working you know. We've definitely got a closer bond the whole family now the three of us ....I don't have the pressures of work I don't have the pressures of having to work late or having to go in on a Sunday or having to work weekends or anything like that I'm at home , there is no pressure again its been terrific. It opened up a whole new world for me and I'm starting to write again, I love writing and I'm writing a book".

Family satisfaction appears to contribute to the psychological well being of heart transplant recipients. Simmons et al (1987), noted that those transplant recipients who were highly satisfied with their family life were socially better adjusted,

experienced lower anxiety, and had greater emotion stability. Family satisfaction is also believed to be critical to achieving successful recuperation in the heart transplant recipient and measures of family satisfaction is seen as an successful predictor of quality of life after the operation.

The experience of serious illness, especially when it is a sudden and life-threatening cardiac event, is a crisis to both the individual and the family. Such events challenge a family's stability, adaptability, resources, beliefs, and assumptions (Leahey & Wright, 1987). The ultimate goal for the family faced with a life-threatening cardiac illness is to reorganise and stabilize its structure and function as the affected member progresses through the acute, transitional, and rehabilitation phases of recovery. Meeting this goal requires the integration of the biopsychosocial consequences of the illness into an acceptable life style for the family (Gillis 1984; Owen 1984). Stabilization of family structure and function is achieved to the extent that the family is able to master the resources necessary to cope effective with each situation during the sequence of events from hospitalization through rehabilitation. Effective coping to prevent family dysfunction takes time and often requires professional intervention and support (Pinneo 1984). In addition, the patient's recovery from an acute cardiac event may be influenced by how effectively the family copes with the situation (Garlione 1984).

Post-transplant life-style is characterized by an improvement in health status with recipients enjoying an increase in endurance and physical function (Wallwork 1985; Lough 1988). There is little doubt that family relationships continue to be affected by the chronicity of illness; however, reports are mixed as to whether the direction of impact is negative or positive. Some researchers have described an increase in family stress and marital difficulties after transplantation (Allender, et al, 1983; McAleer, et

al, 1985) whereas others have detailed an improvement in home and professional relationships reported by heart transplant recipients (Lough 1985; Wallwork 1985).

3.5. Contact with Health Services: A Necessary Evil Vs A Blessing

This category was concerned with how patients feel about being in hospital. Many disliked the environment of the hospital and wanted to go back home as soon as possible while others experienced anxiety and uncertainty about leaving the safety of the hospital. This category also included problems experienced by having to visit the clinics very often.

Contact with Health Services: A necessary evil: This concerned patients' negative feelings about the hospitalization.

6/13 "I used to boast that, I was one of the few patients that I've never been back in the ward once they discharged me but a year and a half ago I was back in the ward when they took me off the Promisulin and I started to rejecting and they sorted that out in 4 days and I was back out.... I'm pleased to say I haven't been in since so I feel it is quite a good thing if you can avoid the ward ..you keep out their road, you come regular to the clinics and as required and they look after you".

According to Fitzpatrick, et.al. (1984), while on the one hand previous periods of hospitalization may be expected to reduce anxiety by providing patients with some familiarity and understanding of hospital routines, it may also serve to increase trait anxiety because they may have a more accurate perspective on the variety of procedures and the extent of discomfort and pain they might encounter.

As Fitzpatrick et.al. (1984) state, hospitalization is a source of stress and anxiety to patients. The hospital environment is novel to patients, and it involves a number of routines and procedures with which they are not familiar. The patients are required to meet and interact with a number of unfamiliar people and frequently have to suffer a loss privacy. In addition they also lose a considerable degree of independence and have to endure separation from their families, friend and work.

9/4 "Being in the hospital at the other end of the country from where you live and your friends and visitors have got to travel and your husbands got to ...that's a big strain... at home it wouldn't have been so bad then when you've been depressed at nights , he used to phone me and I would bubble and cry on the phone because I was so far away from home"

Being away from family and friends and feeling lonely was another problem caused by long hospitalization..

29/1 "I ran into a lot of problems after the operation- I was in the ward for about 3 months so I found that very soul destroying ,it was very confined everyone's living on top of one another, nurses, doctors, other patients, and I felt that you didn't get enough time to be on your own often you wanted to be by yourself rather than sitting, speaking or watch television or things like that".

23/2 "...the problem after the operation was that I was told that the standard time for getting out was about 2 weeks and if I lived in the Glasgow area I would be away but I come from the other side of Scotland and I expected to go to the flats that they have here...and it was about 4 weeks before they let me home...I was pleading with them to let me away for a weekend and eventually they said OK.".

Staying in the ward apart from being seen as an unpleasant event, almost always forewarned of something wrong with their health. So avoiding the ward was like avoiding facing up to likely health problems.

29/3 "As I say the main problem was being stuck in the ward for so long...just to get out even down to the gym I love to get down to the gym and exercise-and you set yourself little targets, and the first one was to get across to the flats just get out of the ward-then I had so many problems I was in and out of the flats and just back to the ward-and again you set these targets and once you are away from the ward you are always that much better you are more relaxed- I found it's very claustrophobic in the ward; I was in it 3 months on and off in the ward which is longer than normal for most transplants, you are much better at home psychologically anyway the minute you come down to Glasgow you begin to get high and tense wondering what they're going to find or if everything's going to be OK."

Other patients reported negative feelings about visiting the hospital in terms of the amount of time they spend.

2/6 "The constant going into hospital...Oh...I didn't like it, I think I'm allergic to doctors. I don't like coming here because I'm sitting around wasting time and I'd rather be in a meeting, in the theatre or playing records doing anything than sitting in a hospital waiting for somebody to come and talk to me. I get very badly for the hospital, my blood pressure is always bad on the days I am here, I've detested every minute of it, I'm glad to go home".

9/6 "Oh I am fine just wish I didn't need to keep coming up here when you see somebody like B. I know B. pretty well I never realized he was so ill, his kidneys

have packed, he looks 10 years older than what he was when I saw him 3 weeks ago that's very sad....".

Coming in the hospital brought her sadness by seeing other's health deterioration and feeling threatened by the fear of her own health deterioration.

The fear of infection was reported as one of the reasons that patients did not like staying or visiting the hospital.

12/5 "I don't like coming into hospital, that's another fear, before I never had a fear of hospitals but I've now, I've got a wee bit of a fear, what about? because hospitals are full of sick folks and I'm very conscious of the fact that I've got a lower immune system right and they 've got something they can give me and I don't want to catch any of the bugs that these folks have got and could affect me. I don't want to catch it thanks very much so I'd prefer not to come into hospital".

Problems also arisen from the clinic visits. Recipients are followed closely in the outpatient clinic to ensure optimal transplant outcome and detect and treat any complications. The problem with clinic visits was that patients have to visit the clinics very often and especially when they live away some other problems were being involved as getting up early in the morning or travelling a great distance. Consequently patients very often were complaining about all the inconvenience accompany the clinic visits and the problems arise.

9/1 "I stay in Dundee ....normally we stay overnight but they are busy in the flats they've had a lot of transplants in the flats across the road so I have to go home and

come back again in the morning, so I was up at half past five this morning-getting do that again tomorrow".

34/7 "I don't like in Glasgow this is too far out from my normal way of life, I don't live like this at home I live solo more or less solo but I like the quiet period where I do what I want to do without interfering with anybody else.....and its terrible sitting out there oh the stress level huh..... you've never seen anything like that, if could measure the stress levels in that waiting room, there really haunting absolutely everybody's going stack, raving mad and there is nothing you can do about it ....I came up to the clinic the other day at nine o'clock in the morning and I got out at five , I had been sitting for six hours for all the treatment that I had to take during that day in the different places.....no more I said, because I do not think it's fair to have to wait and it makes me feel bad. I could simply have the x-rays and go off and have a cup of coffee and do something else and come back and pick it up. But sitting and waiting its terrible thing to inflict upon anybody".

For all the above reasons, reported by patients, hospitalization was a problem for many of the patients. Patients often appeared distressed and they expressed a wish to return home as soon as possible, after the operation.

Hospital stay: A blessing: Concerned patients' feelings of safety about staying in hospital. Leaving the hospital, brought feelings of uncertainty and anxiety of leaving the safety of the hospital and leaving the dependency of 24-hour nursing care which has been established during hospitalization. Some patients found it difficult to function outside the hospital. The prospect of monitoring medications and side-effects without nursing support may sometimes appear overwhelming. The role shift toward independence was anxiety-provoking.

8/2 "I always feel safe when I come into hospital , when you are away from the hospital you feel that wee bit vulnerable, you know if your imagination comes into it to a bit the least wee thing eh wondering if you are all right, but as soon as you get to the hospital for a check up you feel OK you know really safe, I was in the safe hands again, always reliable come up here and get seen to get attended to you.

13/5 "I think the only problem was the day I left the hospital going home for the first time, when I was in the hospital you are all wired up with this new heart and you are all wired up and there are nurses sitting outside with a monitor....and the first the only time I really felt frightened was the day I walked out when they took all the gadgets away and you were in there on your own and there was nobody sitting outside your door to see if your heart was beating properly...and I was frightened that night, I thought if anything goes wrong here and -I think sometimes stories upset you in the sense that somebody said oh I had a heart attack and didn't know anything about it you don't have any feelings -that night I said maybe I'll take a heart attack and won't know anything about it, after the first night was over my fears were gone but it's just you are protected so much at first with all the monitors, and everything is going on and you never think about it , it's only when they disconnect them all and you walk out there on your own, that was a wee bit frightening..."

As it was found in the literature, (Bailey & Clarke, 1989), the discharge from hospital may be stressful. Monitoring of patient's emotional reactions throughout the hospital stay found that patients were not always delighted to be going home. Several patients experienced negative reactions for a number of reasons. Examples were worry about the arrangements of the journey and worry about coping at home with little or no assistance. Some felt the goal of the hospital admission in terms of

treatment or identification of their health problems had not been met. Many patients were unhappy about the short notice of discharge.

From the point of view of stress and coping, as was found in this study, the return home after a period of hospitalization demanded not only physical organization but psychological adjustment to a new situation. The patient needed time to get used to the idea and develop coping strategies.

As it is suggested in the literature (Bailey & Clarke, 1989), how patients will cope on return home will depend upon many factors, among which are: 1) personality factors and how well the illness and the period in hospital have been coped with; 2) how well patients have been prepared for discharge; 3) the degree of adjustment to loss and/or disability and the amount of relearning required for functional independence; 4) support and help from family and friends, how appropriate are the arrangements for continuity of care and how well they work in practice.

3.6. Psychological problems

This category included all patients' reports of how this experience affected them psychologically, including fears, worries , anxieties, and psychological complications from the medication.

The heart transplant process is a succession of stressfully critical periods which requires the patient and their family to effectively cope. Suszycki (1988) states that the heart transplant is one of the most significant experiences patients and their families can have. Heart transplant patients have been found to experience various

psychological problems throughout the transplant process such as anxiety, depression, ambivalence, anger, and emotional liability (Kuhn, Brennan, Lacefield, Brohn, Skelton, & Gray, 1990).

3.6.1. Fear of death

The fear of death was the common fear among heart transplant patients and became apparent with many different expressions.

The process of accepting a new heart was seldom a conscious one but was often revealed in dreams.

24/3 "I do remember having quite vivid dreams for a long period eh of badminton was running on one side of a net with hitting this shuttlecock but it was hitting into darkness and I kept waiting for it coming back and something went through my mind if this shuttlecock doesn't come back again, I'm going to die you know it was just a dream by the time I woke up I'd been sweat it was like a nightmare. Then I thought maybe it should stay on that side in the darkness and the dream altered then it took longer time to come back ...that was a strange dream, every night was the same playing badminton..... I was hitting this thing over a net there was nothing on the other side of the net just blackness where I've been looking around for this thing to come back again hoping it would come back and then it got to the stage I was hoping it wouldn't come back".

The fear of death is been expressed in the above case with nightmares. Fear whether he will pull through, fear of the unknown (darkness). Through this nightmare he is trying also to alter his interpretation of his fears.

Many theorists (Lazarus, 1966; Seligman, 1975; Bandura, 1977; Gatchel, 1980) have proposed that the course of fear and anxiety is dependent on perceptions of control versus helplessness in the face of an aversive situation, and that therapeutic interventions are effective or ineffective by virtue of their ability or inability to increase perceived control on the part of the patient. One of the most comprehensive statements of this position has been made by Bandura (1977), who proposed that a person's level of fear is primarily determined by their perceived "self-efficacy", their ability to escape from or master aversive situations.

8/13 "The biggest fear is the fear of death, you are frightened of dying right enough, nobody wants to die , and you are on limited time with the transplant".

Feelings of fear of death never completely vanished but the degree of acceptance increased.

4/9 "I think everybody's got a fear of death to a certain extent, it's not a fear of dying it's the fear of how you're going to die .....but my attitude towards the finality of death has changed because I have no fear of it you know, I think the only fear most people have is the regret of what you are leaving behind, you tend to be nosy you won't be there and life will still be going on without you , so you are a bit concerned that people will be having a good time without .....but the fear of death .....the inevitable or what happens in the future as long as there's no pain attached, no problems or no extreme pain like an accident....."

Fear is activated when a person is physically or psychologically exposed to a threatening situation that can be identified and described (Stuard and Sundeen, 1987). Fear can be either adaptive or maladaptive. As an adaptive mechanism fear: alters the person to seek medical attention when new symptoms or exacerbations occur; helps the person anticipate the stressors of the illness and mobilizes problem-solving and other strategies to cope with the identified stressors (Lubkin, 1990). Fear becomes maladaptive when it is more intense or of greater duration than is warranted by a particular stress. In such a circumstance, fear no longer serves the purpose of altering the person, it actually causes a decline in adaptive functioning (Green, 1985).

As Lubkin (1990) state, during intense emotional reactivity because of the fear, patients will need reassurance that their feelings and concerns are normal, and action taken need to be supportive. Active listening need to be used and the patient encouraged to express his/her fears. The health professional's verbal and non-verbal communications should convey an awareness and acceptance of the patient's feelings, and feelings and concerns will be disclosed. Extending hope appropriate to the circumstances can be very reassuring to fearful patients and acts to reinforce their confidence in the care and support they receive (National Institutes of Health, 1982).

3.6.2. Fear of the unknown / uncertainty

Uncertainty is a perceptual state, occurs when internal or external stimuli are vague or unclear. Thus, uncertainty contributes to the perception of events as stressful and may impede coping efforts (Lazarus and Folkman 1984; Mishel 1988).

In the illness experience, uncertainty, according to Mishel and Braden (1988) has four forms: ambiguity concerning the state of the illness, complexity, regarding the treatment and the system of care, lack of information about the diagnosis and seriousness of the illness, and unpredictability as to the course of the disease and prognosis .

Uncertainty is usually threatening because a clear perception of what will happen may not be possible. Uncertainty limits the individual's sense of control over the danger and thus increases the sense of helplessness. When individuals cannot decide on the path of action, and resolution of the problem is unavailable or not possible, fear, excessive worrying, rumination, and anxiety can result. Emotions associated with uncertainty, however, can also be positive because when the person is unsure about the diagnosis or the severity of their illness situation, it may permit them to expect that things will be all right (Hilton 1992).

13/5 " I don't say well I'm going to live for 10 years who knows anyway nobody, you don't get any guarantee with life."

Patients often experienced a sense of helplessness, of being unable to do anything to extend life.

4/7 "We keep saying there was never a guarantee given when you got a transplant, so you don't take any guarantee, what you've got to know is that it's like a cheap watch it could go on for a long time or it could stop, that's it no guarantees given, we all say that this is part of life well I've had 3 more years than what I would normally have".

14/3 "You don't know where its all going to land. You still have your down moments every now and again wondering if you are ever going to get any better".

2/6 "This thing its affected my confidence quite a bit for a long time, because I did worry if I ever go away, because I like travelling and I began to worry if I would ever get away again".

As uncertainty was generally associated with anxiety, a careful assessment of emotional state could help to identify threatened individuals. By assessing it was possible to determine the degree and type of uncertainty and whether those uncertainties could be reduced or alleviated.

11/7 "Well there is a problem, my fear is of not having any sensation of pain-whatever in the heart because I don't have any nerves eh the nerves got cut and then I may not be aware of a problem arising in the future. If I canny feel the pain I might no be aware if I'm having some kind of heart attack or whatever, I might try to carry on and obviously make things worse".

Rotter (1966) conceived of generalized control expectancies as having their greatest influence when a situation is ambiguous or novel. Under conditions of ambiguity which is used here to refer to lack of clarity in the environment, situational

cues regarding the nature of the outcome and/or the extent to which it can be controlled are minimal. In the absence of clear information, the situation is like a projective test, and the person makes inferences based on general experience and personality dispositions, which include beliefs, to understood what is happening. The greater the ambiguity, the more inference is required and, consequently, the more influence person factors have in determining the meaning of the environmental configuration (Lazarus, Eriksen 1951; Schank 1977). When a situation is highly ambiguous, a person with an internal locus of control might be expected to appraise the situation as controllable, whereas a person with an external locus of control might appraise it as uncontrollable.

Some uncertainties can be reduced or eliminated through the provision of further knowledge or/and clarification. Distortions, illogical conclusions and misunderstanding can be corrected. By listening to the patient and interpreting areas that are still unclear some stressors can be defused. Medical staff can decrease the patient's uncertainty by helping them interpret events more clearly and helping them to be aware of alternatives and consequences of alternatives. At times a sense of powerlessness can be reduced by having the person clarify stressors. Through discussion, there can be identification of areas in which to seek assistance or to make decisions. This helps patients to see where they have control over a stressor (Hilton 1992).

14/5 "You get uptight sometimes when you think that you've got something else coming like suddenly developing something, maybe say there's a lump on your elbow or something like this and the you worry what's going to happen next ".

Unpredictability refers to the unknown involved in heart transplantation. The initial unknown is whether the precarious condition of the patient can be maintained until a heart is available and whether the patient will survive the surgery. The instability of the postoperative period follows and culminates in the unpredictable occurrences of infections, rejections and secondary illness. Life span with a heart transplant is known to be limited, therefore, the events remain uncertain with the patient's status being subject to sudden and catastrophic change (Mishel & Murdaugh,1987).

3.6.3. Depression

Duitsman et al (1993) found in their study that, one of the most common psychological disorder in heart transplant recipients is depression and this is significant because depression has also been shown to affect recuperation. The data of their study supported the contention that depression is associated with perceptions of diminished quality of life.

15/12 "It's easy to become quite depressed especially with all these drugs that you get and you waken up in the morning and think that'll be 20 tablets to take and then when you go to bed at night you've got another 10 and you think to yourself oh 30 tablets, I'm rattling like a pill box, oh you are getting depressed".

Fitzpatrick, Hinton, Newman, Scambler, & Thompson, (1984) stated that, when an individual is very ill and weak it can be difficult to distinguish exhaustion and physical discomfort from symptoms of depression. This is not only the problem of cause and effect, but that symptoms such as weakness, loss of weight and appetite,

and insomnia are common to bodily and mental changes. Unpleasant physical symptoms are a self-evident basis for psychological distress. Patients can describe for example, how their continued pain has got them down. In parallel, investigations have demonstrated that the longer a painful illness persists, the greater the prevalence of depression (Hinton 1963).

18/1"I feel bad all day- when I came in on the 20th of March I took a dizzy turn, then I took a bad turn, from then to now I've sort of went downhill up a wee bit downhill, I feel done in, I feel as if I'm getting nowhere.....this kind of thing I've got affects your mind as well -it affects it both ways, makes you sort of knock things over things, don't work right and it depressed you a bit- its like being stuck in the wall and you canny get up and you keep trying, give it a step and you keep falling back into the wall and that's how I feel....."

10/1 "I was more down than up you know with J. leaving and I still feel quite hurt that she left.....That was the biggest upset that I ever had and I got depressed."

Watts et al (1984) and Jones et al (1988) found that depression is difficult to assess in cardiac-transplant recipients . The prevalence of symptoms such as a lack of energy, poor concentration and weight loss, which may be attributable to the patient's physical condition particularly among those with congestive cardiac failure, were similar to those that are found in patients with depression. Thus, these symptoms may not be good indicators of depressing feelings.

As depression was found to be associated with unfulfilled expectations, education with the patient and family could reinforce the concept, that heart transplant

recipients had a reasonable likelihood to achieve a normal quality of life, and also avoid self-fulfilling negative role expectations.

3.7. Was I prepared for the heart transplantation?

This category included patients' opinions about the importance of being prepared for the heart transplant and the consequences of not being prepared. Patients' understanding of being or not prepared found to have been influenced from their expectations for the heart transplantation. Most of them had high expectations believing that the heart transplant is going to solve all their problems and improve totally their health. Many heart transplant recipients saw the transplant as a trade-off, curing the heart problem but creating new health problems to cope with. Some patients reported that the shock and confusion created by the initial diagnosis appeared to block the understanding of necessary information. Very often patients blamed the nurses and the doctors of not giving them adequate information. Other patients understood the inadequate preparation as due to their own limitations, either because they were very ill in pretrastplantation period, or being assessed and having undergone the operation without having enough time for preparation.

The literature suggests that preoperative low cardiac output syndrome can hamper effective patient teaching as much as postoperative steroid therapy (Cooper et al., 1984).

According to Rakel (1977), when there is a stress of a serious, progressive illness, closure of communication is frequently seen in the home, and closure tends to be linked with avoidance, avoiding any discussion of disease-related information.

15/1 "I said to them you know you never told me it was going to be like this and they said oh yes we did but you just weren't listening.....Before the operation all I was interested in was getting the transplant all you wanted to do is get better and then after the transplant you are assuming that its all going to be bed of roses but it isn't, there are all kinds of other problems that come along the line, hiccups and they call them peaks and troughs- these kind of things that happen to you that you are not fully prepared, for example that you have to take tablets for the rest of your life. I didn't realize it was going to be quite like this".

Christopherson (1987) argues that prior knowledge of transplantation and the hope it offers, however, often hides a lack of understanding of transplant limitations.

As O'Brien (1985) states patients with an illness of sudden onset, and who usually are younger, have little time to make the mental adjustments to their condition before moving into the next stage of their illness.

6/14 "I had been through a traumatic experience after the operation because , when I was told that was going to get a heart transplant I didn't have a problem, I never had a heart attack I didn't have angina , I

was never really in any terrible pain, I never had any pain in my chest or unable to well breathing".

3/5 "I was actually brought in and assessed and then 2 weeks later I was in for the transplant I was only assessed two weeks before and then brought straight in so it was quite quick, it was quick .....I found more after the transplant, if I had been told certain things then I would have been prepared for them -I honestly was convinced that when I had my transplant one day I would throw the tablets away the next day, I was only on 6 tablets prior to my transplant I'm now on 26, but I was convinced in my own mind when they came and said right you on for a transplant and you'll feel this and be much better and all the rest, at the time I was convinced that once my transplant was successfully done I would be on no tablets or I would be on very few , and eventually I realize that were multiplied by hell. There are certain things that I could have been told and I would have been happier if they had told me".

13/2 "I'm very grateful for the nurses and the staff who really helped me at the beginning, they give you the encouragement and they tell you things that are likely to happen to you so when something happen you remember the nurse told you this might happen, or the doctor said this might be a possibility."

11/10 "I had to go for the transplant but it took a lot of getting used with the idea-maybe they're a wee bit slack on the psychological side where they can give people help that are having problems, I mean some people are that ill, they don't know anything or do not get much time to

think about , or come in and get assessed and within a day or two they're in and had their operation. In my case I waited about a year from being assessed to getting the operation and that's just time for you to worry and get uptight and things develop and you are worse".

Patients often had high or even unrealistic expectation about the transplant and they got disappointed when the reality did not meet their expectations.

35/1 "I found it quite frustrating at first you know to get back to fitness and health....I thought getting a new heart I would be jumping out of bed doing great things ...it took a while...quite a bit of hard work, a lot of exercise walking".

His expectations were higher and it was disappointing for him to find out that he was unable to do things soon after the operation or that the recovery process required time and effort.

28/1 "I don't think anything can prepare you for how you are going to feel we keep being told and we know that we're individuals but I couldn't imagine how I would really feel eh I thought the operation itself was the big thing and if I got through the operation I would be fine but I don't think that I was prepared for what might go wrong or the medication just a lot of things that did happen, I suppose I was unfortunate".

Long life is not the expectation of a heart transplant patient although all hope for it. Patients could perceive transplantation as not an

operation to make them "brand new", but rather the exchange of one set of symptoms to another. Patients need time, before the operation, to consider all the issues involved with the heart transplantation. They need to accept an organ from another human being, the inevitable death of another person which makes heart transplantation possible and that heart transplantation carries risks and uncertainties and accompanied by possible complications of this treatment. Health care providers can play an important role in preparing patients-prior to transplantation- for what to expect after surgery. As it is also described in the literature, in a study by Hyler et al.(1985), about the role of nursing in a support group for heart transplant recipients, the support group is a workable intervention for addressing some psychological aspects of care. As Hyler et al stated, giving and receiving factual information, sharing opinions and suggestions and validating one's views provide an emotionally positive climate for both patients and families before and after transplantation. Transplant candidates achieve a better understanding of positive adaptive measures undertaken by patients who have already experienced the transplantation. Discussions involving health, family interactions and quality of life enable patients to both give and receive support during and after hospitalization.

3.8. Am I a different person now?

This category was related to patients concerns about changes occurring in their lives after the heart transplantation, including changes in life and life-style, changes in feelings, attitude, and personality.

Patients often reported changes in their attitudes.

2/4 "I' m conscious of my age for the first time in my life, I think before the op I regarded myself as being about 26 whereas I realized I'm actually 43 and I am going to have to start behaving like an adult whereas before I think I didn't".

Changing their life-style meant changing the behaviours that put them at risk.

8/12 "I have really changed my priorities I think I'm more inclined to watch what I'm doing more, to be more conscious of what I'm eating...".

Patients sometimes worried about changes in personality that were related to mood swings as a result of steroid therapy.

4/1 "The only problem not to me but its been brought up recently by my family is that my mental attitude has changed. My wife reckons that people who have heart conditions, their mental attitude changes, you know without them knowing it, I think you get more aggressive or less tolerant, I don't know whether this is true but its been told to me....I mean I had my heart transplant 3 years ago and I seemed to be less tolerant, small things like the matrimonial side of it irritate you more than they normally would... but I started to think before I act or speak now...."

Patients often spoke about changes in their emotions and feelings.

2/4 "I'm much more emotional now than I used to be, I was more concerned before about not showing them, as now I tend to show my emotions much more I'm possibly more affectionate than I used to be, whereas I was a very typical Scottish male who wouldn't show any emotion. I find myself reacting to tear jerkier films-when something in a film is specially designed to produce an emotional reaction where I would normally have laughed at it previously I now find myself being caught reacting to emotion. I'm much happier person certainly a more contented person that I was before.....I'm much more aware of my emotions now, I demonstrate my emotions much more and I am much less likely to worry about what other people think".

2/5 "I think the basic thing that has changed is the emotional part, I'm much more aware of my emotions , I also demonstrate my emotions much more and it's much less likely to worry about what other people think about me. I demonstrate my emotions publicly much more than I did before, I'm not a cold person but I would sometimes get frustrated in public .....probably it's the case of being alive, the joy, and the alternative to sitting here now than to be 6 feet under and that makes you feel quite happy."

Most patients expressed heightened emotional response to things that others take for granted. Patients expressed a full gamut of feelings. Some feelings were reported as having changed over time as others were recurrent.

3/6 "I have become more tolerant after the transplant....life is too short, there is no point in moaning about things that I would, my priorities have changed totally ...I've never put too much importance on money because I've never been in a position where I didn't have any, but now it seemed less than what it was you canny take them with you, I mean I could be six feet under in a box... I look at things different, open my eyes a bit and take my time, I've slowed down-its amazing what you can see when you slow down and open your eyes!".

9/5 "I also found that I'm a lot more cheerier person and got a more jovial personality to that what I had before maybe that's because you've got a second chance at life that makes you see the funnier side of things that I never seen before. The simple things in life like the birds, gardens, flowers, nature I get a lot of pleasure from that, I mean that I feel that more now. I think I'm also much easier pleased about things than what I would have been before. I've changed quite a lot and probably for the better-I'm more more thoughtful towards about my husband about how he is sleeping, is he depressed or anything".

13/6 "I spend more time with my family now and I'm grateful for that I've got time to spend with them. I fully intend to do and hopefully be a better person for it all, and learn something from it all and be a better person, I want to just have a happy life too. I don't think material things are important to me now, because before you know Oh I wish I had a new pram, I wish I had a bigger house(laugh), these things aren't important anymore, you realize how silly they are, how silly they are to worry about, all these financial things and holidays-saving up to go a specific holiday,

that's not important anymore. What important now is to be happy with what you've got and I think a lot of good has come out of it, a lot of good has come out the operation apart from doing me good and letting me live, I think I've learned to be a better person within myself and I think about other people and how other people feel".

4/9 "My attitude towards the finality of death has changed because I have no fear of it, the only fear is the regret of what you are leaving behind you, you tend to be nosy, you won't be there and life will still be going on without you so people will still be having a good time without you, but I don't have any fear of death, what happens in the future as long as there's no pain attached no extreme pain , that's no problem".

15/4 "I've become more impatient in some ways, I got upset recently waiting in a supermarket in the queue, is all waste of time and all are precious minutes....I want things to keep happening all the time , I don't like hanging around, sitting in a traffic jam, I could be so annoyed because there are so many things I could be doing".

As Mayou et al. (1978) stated, personality changes in the patient increase tension and stress in family.

4/1 "I seemed to be less tolerant, small things irritate you more than they normally would...but there isn't anything else I can elaborate on because I don't know whether this has to do with the transplant or just with the ageing process, because you know I'm 56 now so it might be just

that you are less tolerant of the rest of the human race....or because you know the steroids apparently gives you mood swings..... ".

As it was found in this study, and was illustrated in all the above categories, heart transplantation brought changes in many aspects of the recipients' lives; as physiological, socioeconomic, and psychological changes. Consequently changes in feelings, attitude and personality occurred. Heart transplant patients needed to adapt themselves in the new reality and confront with all these changes. Development of coping skills required in order to effectively deal with the changes in their lives and effectively adapt in the new reality.

3.9. Summary

The ability of heart transplant patients to cope not only with the severe physical stress of suffering the rejection process, as well as the troublesome side-effects of the steroids and immunosuppressive drugs, but with the psychological meaning of the loss of their own heart, and the concerns of having somebody else's heart inside them was remarkable.

Houser & Konstam (1992) stated that an awareness of the medical aspects of heart transplantation is necessary in order to understand what the person and family has been through. The heart transplantation process is demanding and requires rigid adherence to a medical goals where understanding of functional limitations and the effects of medications on performance is needed. Understanding the psychological implications of the heart transplantation process is necessary because of the

significant role that patients' psychological processes play in their daily functioning. The heart transplant patient and their families need to develop strong coping methods that effectively deal with the stressful events of the heart transplant process.

Health professionals need to learn not only how to care for heart transplant recipients but also to understand the whole array of psychosocial implications of heart transplantation.

CHAPTER 4: Somebody else's heart inside me

4.0. Introduction

The category "Somebody else's heart inside me" was related to the patients' concerns about the donor's heart and how getting somebody else's heart might affect their own personality; guilty feelings for the donor's death and feelings of gratitude towards the donor's family; and concerns about their own heart. The sub-category "What happened to my own heart?" was not saturated, as only few of the patients reported worries about their own heart. The sub-categories "I'm grateful to the person who gave me the heart" and the "Will the new heart change me" were fully saturated as all the patients reported feeling guilty about the donor and worrying whether the new heart would change them.

According to Rogers (1984), for the patient, heart transplantation means more than an operation. It is not simply a question of replacing an organ that no longer functions. Patients have to cope with a dual challenge: the loss of their own heart and the acceptance of a donor heart. According to Bunzel et al (1992) psychologically, losing one's heart and having it replaced by somebody else's, an anonymous donor who has the target of disease or accident or even suicide, can mean a threat to one's self-concept. Feelings of guilt about the donor's death and the feeling of being always grateful are present.

4.1. I'm very grateful to the person who gave me the heart

Most of the patients who were interviewed, admitted feeling grateful to the donor and the donor family for their decision to donate the heart.

14/8 "I was very grateful, I'll be indebted all my life to the chap that gave it to me and the surgeon that done it. Getting somebody else's heart it's amazing, they put something in there that can make you better....I've never thought about it that way where I got it, they told me it was a lad maybe in his early twenties and that was all, I didn't want to know his name or where he came from , but they told me my heart is running perfect so I was quite happy with it".

19/8 "When I was thinking about the person that donated the heart I thought it was big decision for the person that's donating their organs but I feel good about it now, I know they are getting something out of it as well, the persons no died in vain , and I feel good about it."

Even though most of the patients expressed regrets that a person had to die in order for them to receive a heart, they also voiced gratefulness and appreciation to the donor family.

12/1 "After the operation I was euphoric and that feeling was with me for three days and then a strange thing happen, I started to grieve, initially I felt that I would have loved to have been able to speak to the people whose relative had given me the heart, you know I felt a need to be able to thank somebody for the gift of life , and that was a barrier that I couldn't talk to these people.....I haven't really got over that, there are times when you waken up in the middle of night and you've got your own thoughts and my thoughts go back to the fact that somebody had to die to give a heart. That sound strange but not being able to actually go up to somebody and thank that you allowed your son, daughter, your mum, your dad whoever for their heart to be given to me to give me this life , that was difficult. I must admit I still grieve for that person I think about that person a lot".

Many patients reported feelings of guilt about the donor's death.

11/5 "I couldn't come to terms with that very easy the thought of getting somebody else heart, I used to lose sleep at night because I was thinking there was a healthy person somewhere that had an accident and gave you the heart and that used to make me lose a lot of sleep".

According to Castelnuovo-Tedesco (1978), quite regularly heart transplant recipients have thoughts of having robbed the donor of a vital part, as a result of which the donor has been killed or injured. These thoughts, in turn, stimulate regression, primitive guilt, and fears of punishment and retaliation.

4.2. What happened to my old heart?

Some patients developed grief reactions in response to the loss of their own heart.

12/2 "And then I had a big problem, well to me anyway it was a big problem, I started to grieve for my own heart that's (laugh) was the strangest thing in the world I think isn't it? I got really worried about what had happened to my heart , what have they done with it you know? my heart was important to me for forty odd years and suddenly its away, my mum and dad gave me my heart and I've gave it away, what happened to it?, then I felt pretty depressed. Then nurses told me that it's in the University building in a big jelly jar, it's being used for research so the minute I know that somebody hadn't just taken it and flung it in a big fire and burnt it I was OK. You see I'm a Catholic like-I know a lot of people believe in cremation but I'm not into this sort of things, I'm going to get buried with somebody else's heart and somebody got buried without a heart and I couldn't bare the thought of somebody taking my heart and slinging in to the fire".

According to Moos (1986), the grieving for a loss entails a progression from an initial reaction of numbness or disbelief to a growing awareness of pain, sorrow-and often anger and a preoccupation with the lost object-and gradually to a reorganization in which the loss is accepted and equilibrium restored.

In order to give real assistance, care givers may need to know the sequence of phases in emotional processes of grieving and the inevitability and value of the expression of negative emotions such as anger or sadness.

4.3. Will the new heart change me?

According to Allender and colleagues (1983) during the post surgical period patients must come to accept their new heart as their own. While patients are taught pre surgically to think of the heart as merely a pump, the symbolic nature of the heart often complicates their acceptance of its replacement.

The heart, with its associations to vitality, emotion, and the soul, and all the mythological qualities ascribed to the heart, was believed to pose special difficulty for the recipient to assimilate into the self, and complicate the recipient's acceptance of the organ.(Shapiro, 1990).

As Rauch (1989) states, many transplant professionals generally agree that psychological rejection of the heart is sometimes associated with physiological rejection.

Patients in this study often fantasised about whose heart they have, and wondered how this might affect them.

13/4 "I wondered if I've changed, you know everybody talks about your heart, heart broken, and I wondered how much of you was within your heart how much of your feelings. I wondered if I'll be different person altogether because I've got somebody else's heart, you put so much feelings towards the heart but you know your feelings are not in your heart, your feelings are obviously in your mind. That was something I thought a lot about I wondered how you would feel personally but it doesn't make a difference at all, so your feelings are not within your heart they are within your head and I still got the same head(laugh)".

Patients often denied the emotional impact of getting somebody else's heart. Denial seemed to help them to cope with their concerns about the likeness of their personality having changed.

35/6 "I knew it's not like getting the brain, the main part of the body, I just thought has this changed me in any way but then I thought that its not going to change me because its like a water pump in a car, if your car breaks down and the water pump or fuel pump breaks down you just replace it and that's basically what your heart is doing so its pumping the blood and oxygen round your system so I thought well it doesn't change your car so its not going to change me , that's how I felt about it and it didn't affect me or bother me one little bit".

4.4.Summary

As Mai (1986) stated, concern about the donor organ involves concepts of death and dying and coping with ambivalent feelings toward the bereavement of the donor's family, whereas adaptation to the graft involves the individual's personal image and concept of the

heart and its effective connotations. This however, requires a psychological stability that many heart transplant patients, at least three months after surgery, do not yet have.

Kuhn et al (1988) in a study about psychopathology in heart transplant recipients, reported 31% of their patients expressed fantasies of personality change related to the donor heart. Kuhn et al did not regard these fantasies as having any general adverse effect on the patients. Indeed, these fantasies may have more impact on acquaintances than the patients themselves, since most patients ultimately deny the emotional impact of having within themselves the organ of another person (as illustrated in the 13/4 and 35/6 extracts).

According to Castelnuovo-Tedesco (1978), the donated part achieves mental representation and comes to represent the donor in part or as a whole. The transplanted organ functions as a new introject and one has an opportunity to observe how the new introject is assimilated into the self-representation, as well as the conflict and struggle that this process stimulates. It is not infrequent the occurrence of serious emotional disturbance and, occasionally, of psychosis, or other primitive psychological manifestations.

The propensity to identify the transplanted part with the donor and endow it with the donor's more outstanding characteristics may be resolved only partially by keeping the donor anonymous. Providing clear information could help the patients to overcome and get rid of their vague fantasies and assumptions associated with the donor's heart or their own heart.

CHAPTER 5: Coping

5.0. Introduction

The category 'Coping' concerned the different coping strategies patients in this study employed in order to deal with the problems that accompany the post-operative period of heart transplantation. A variation of coping strategies, as found in this study, used by heart transplant recipients post-operatively. Three coping strategies, "Acceptance", "Denial", and "Avoidance" were found in this study to be the coping strategies used most frequently by heart transplant recipients. Most of the patients used "Acceptance" as one of their most frequent coping strategies, by accepting the problems as part of treatment and "the second chance in their life. "Denial" and "Avoidance" were used very often by patients who tended to deny or avoid any involvement with any unpleasant thought or hurtful situation. Categories such as "Blaming others" and "Changing priorities" were not saturated as only a few patients reported using these coping strategies. However, these categories were included as they offered richness to the results and explained the wide variation of coping strategies employed by the heart transplant patients.

5.1. The coping strategies used by the heart transplant recipients

An attempt was made to elicit information from patients about how the heart transplant was appraised, the type of coping strategies that they used, and whether these strategies proved effective in alleviating the problem and/or the patient's

emotional distress. A large number of coping strategies, as they are described below, were found to be employed by heart transplant recipients in this study.

5.1.1. Acceptance

Acceptance involves coming to terms with the limitation and restrictions imposed by the problems experienced, the changed life-style, and the limited horizons, learning patience and not wishing to do more than one can (Suls & Fletcher, 1985).

4/8 "I know a lot of people, you meet them in the clinic here, they've got different mental attitudes, some of them are still complaining because they've had to come back with rejections or side-effects or picking up infections but that's just got to be coped with as it comes, you've got to stay away from crowds because you know that your immune system is low, but I still feel great I've always been an optimist rather than a pessimist".

According to this patient, being aware of the restrictions and accepting them as part of the compliance to the regimen, was the best way to deal with the situation.

6/14 "A good friend that was here who went back to work and I don't know whether that's upset him but he finished up by taking a minor heart attack in his new heart ...we all thought he put too much pressure on himself because he was working away down in London driving home every fortnight in his car.....we feel a bit shaken more or less all decided that if we can survive with what we've got without working we'll just keep ourselves occupied with working around the house and playing golf because there certain things you get involved in the home ,push

yourself far but all of a sudden you just stop and have a cup of tea and have some rest and you just couldn't do that at your work...you couldn't switch off for half an hour...you'd be pushing yourself on and by the time to finish you'd be a total wash out and finish back up in the ward just because you've overdone it ".

8/3 "I've heard one or two saying you know the side effects and so on but you could live with any side effect that I've come across and then you are getting used to the medication and sort of thing, it's better to live with the side effects than not to live".

14/3 "Life was quite good you just got to get on with it".

14/5 "You've just got to take every day as it comes, every day is a bonus.....you are taking drugs all the time maybe 30 pills a day or something but you just live with that, it's started away you'll never cope with that but once you get started it's all right"

9/2 "You take these things(symptoms she experience) as they come and accept them and just get on with life because you are still living and I've got grandchildren along the road that I would never have seen if I didn't have my transplant".

It seems that patients who accept the reality of the stressful situation, such as the complications and side effects of the long-term medication, are engaged in an attempt to deal with the situation.

14/6 "I've leveled out now so I know my capabilities, what I can do and what I can't do....but I took that virus that was me going downhill- I suppose it's just one of these things you've just got to put up with it ".

According to Lubkin (1990), once the intensity of feelings about the losses imposed by chronic illness are greatly diminished, clients accept the fact that even though many choices in life are eliminated, many satisfying and fulfilling ones remain. At the stage of acceptance, there is a renewed interest in life. Energy returns, social relationships once again become a source of pleasure, and activities that are still within the client's level of functioning are resumed or developed anew. Daily behaviour becomes more routine and the physiological problems that plagued the client during earlier phases become normalized. At the end of the grieving process, chronically ill clients accept that life is forever different but they recognize that they have strength and the ability to carry on and even enjoy future happiness (Green, 1985).

5.1.2. Denial

Patients often used skills aimed at denying or minimizing the seriousness of an event.

Denial has a protective and adaptive function in heart transplant patients, as long as the threat to the individual is so great that it cannot be replaced by more effective crisis management (Bunzel et al, 1992).

Patients often verbalized their denial saying that they were aware of avoiding thoughts and feelings about the donor. Patients who denied any emotions toward the unknown donor, explained that there was no reason to talk about the graft and the donor.

30/8 "I don't like talking about it, I think the donors parents are donating their son or daughters organs whatever they may be, I don't know who it is and I don't want to know. I thank them for that I got a heart out of it and I'm quite happy I feel sorry for them, but I never talk about it I never ask any questions where the heart came from".

Research findings (Bigos 1981; Levenson et al 1984; Levenson et al 1989; Faller 1990) support the fact that denial can have a positive effect during the first post-infarction days when the individual's resources are insufficient to cope in a more problem-focused way. It is important to understand the need that denial meets for the person in adjusting to the loss and that denial is the first stage of the loss and grief process. Confronting the patient with reality too soon may not serve any therapeutic purpose and may do more harm than good (Robinson 1993).

Some patients did not deny the severity of the problems but did seem to deny the impact of these problems on themselves.

35/6 "I knew it's not like getting the brain, the main part of the body, I just thought has this changed me in any way but then I thought that its not going to change me because its like a water pump in a car, if your car breaks down and the water pump or fuel pump breaks down you just replace it and that's basically what your heart is doing so its pumping the blood and oxygen round your system so I

thought well it doesn't change your car so its not going to change me, that's how I felt about it and it didn't affect me or bother me one little bit".

Kuhn et al (1988) in their study found that most patients deny the emotional impact of having within themselves the organ of another person. A variety of defenses are used, such as depersonalization of the donor heart ("it's only a pump") and repression ("I never think about it"). Whereas Mai found that this type of emotional denial of the transplant was highly prevalent (18 of the 20 patients in his series) and believed it was normal and adaptive, Kuhn et al (1988) reported that out of 12 of their 27 transplant patients who showed a strong need to deny emotions toward the graft or the donor, 10 had a diagnosable psychiatric disorder, and all subsequent behaviour management problems occurred within this group.

31/10 "I think the best policy is not knowing what's going to happen next, I think the unknown is better than what you want to happen".

Kubler-Ross (1969) suggests that denial gives the individual time to come to terms with the situation and to develop other coping strategies.

38/4 "If somebody ask me how do you feel I'll say fine and I don't go into details about it, because well I don't think it really concerns anybody else, its something between me and myself, and I don't have anything to say to them".

Sometimes the denial took the form of refusal to believe that the stressor exists or of trying to act as though the stressor was not real.

31/3 "I personally do not like having any contact with them, because they would express roans and they had different aches and pains that things that I've got to go through and sometimes I think its better not knowing what lies ahead".

In a study by Streltzer et al (1983) about coping with transplant failure, the authors explained differences between grief and denial (two ways of coping with failure) focusing on the effectiveness of denial. The authors found that deniers almost uniformly felt that they had a great deal of support from family, friends, and staff, as grievers seemed to be much more mixed in their experience, with many of them feeling less than optimal support. Deniers more often reported being well prepared for the possibility of transplant rejection than grievers. It may be that realistic appraisal of the possibilities of success with transplantation is predictive of the ability to effectively use denial. Deniers seemed to have more positive reactions to returning to dialysis than grievers. In conclusion, the findings indicated that grief is a common but by no means universal reaction to transplant failure but denial is a commonly used, and can be an effective coping mechanisms. So Streltzer et al.(1983) suggest that the effectiveness of denial as a coping mechanism should be recognized and supported when present. Grievers should be recognized and expression of their grief should be facilitated; in contrast, deniers should be supported and their acknowledged denial and not forced to ventilate feelings.

In a study of the psychological adaptation of cardiac transplant patients, Mai (1986) reported that denial was the most striking finding: 90% of patients expressed denial towards the graft, towards the donor or towards both. Mai also states that this "graft and donor denial" may not be maladaptive but rather may be an aid in emotional adjustment. Patients with greater emotional distress may need denial more than others. Conceivably, patients with greatly reduced coping abilities cannot face

such a difficult emotional task without extensively restoring to this defense mechanism. Patients need time to grief and think and organize how they can cope with the rigors of the heart transplant protocol. Denial, this defense mechanism may gives the needed time for grief and makes the emotional adjustment easier (Mai, 1986).

According to Lazarus (1984), denial in the context of illness is considered ineffective because the person fails to engage in appropriate problem-focused coping (e.g., seeking medical attention or adhering to a medical regimen) that would decrease the actual danger or damage of illness. Hackett and Cassem (1975) and Hackett, Cassem, and Wishnie (1968), who observed both positive and negative effects of denial in a heart attack, they found that during a heart attack denial was damaging because it obstructed the effort to get medical help. After a heart attack denial facilitated recovery and resulted in fewer deaths from subsequent attacks. Cohen and Lazarus (1983) reviewed other studies in which the same principle seemed to apply, that is, denial proved helpful while the patient was still in the hospital and seemed to have negative consequences when used after leaving the hospital.

Nurses and other staff need to be able to determine the adaptiveness of denial. They need to understand when is the right time to intervene and either to foster their coping through denial or to suggest to the patient to abandon this defense mechanism and employ other ways of coping.

5.1.3. Avoidance

Avoidance strategies, involve these strategies that focuses attention away from either the source of stress or away from one's psychological/ somatic reactions to the stressor (Suls & Fletcher, 1985).

Lazarus (1983) suggested that avoidance-type strategies may have positive value at an early stage of coping when the person's resources are insufficient to cope in an instrumental problem-focused way. Only later, will the person be strong enough to come to terms with the reality of the condition and struggle to cope in a practical, problem-focused sense.

Avoidance has also been shown to be of benefit to patients recovering from a myocardial infarction (Hackett, Cassem, & Wishnie, 1968; Cassem & Hackett, 1973). A period of non-attention to psychologically loaded issues may afford the opportunity to go along with whatever is expected. Such an avoidance may permit the individual to co-operatively accept certain aspects of treatment.

Avoidance often took the form of avoiding any involvement with unpleasant thoughts.

4/7 "I never think about what could happen in the future you know, I just heard yesterday one of the lads who got done before me he died with cancer, so you know that things could happen but I don't accept it ".

17/10 "I can't remember half of the things that were done because basically when I go out of here I forget about this place, I go away, I live my life".

28/3 "I found I didn't want to see anything hurtful I couldn't read the paper you know the Bosnia situation I didn't want to think about it too deeply, I didn't want to hear anything nasty that there were children being abducted, raped, and all these things I didn't want to know about it , it was almost as if I was an open would and it would hurt too much. I couldn't watch anything for months...I always felt very tender ...I couldn't cope...I didn't really want to know anything , it was enough just to be coping with my situation".

14/3 "I didn't want to be bothered with anything you know everything seemed to be coming down on top of you ".

7/2 "The day the bleeper went for me going for the operation I just went kind of switched off and forgot about it and let my wife to take care of all the details .....it was a case of the mind went blank and you kept it that way, I just didn't want the idea of thinking about it and that was my way of dealing with the deal".

8/9 "I never thought about the donor I mean what I thought about was that somebody had given me a gift right enough it was marvelous, I was pleased to have it I never thought about the person that gave it to me well maybe it did cross my mind but I never really gave it much thought, I was delighted to have it and it was terrific that someone had done this for me".

Avoidance was found in this study to be one of the most common coping strategies used by heart transplant patients, mainly avoiding being involved in unpleasant or harmful thoughts. Suls and Fletcher (1985) found in a review of the literature on coping strategies that, avoidance was associated with more positive adaptation in the short-term. In terms of long-term outcomes, avoidance indicates

better outcomes initially, but with the time, it was associated with more positive outcomes. As Lazarus (1984) argue, denial and avoidance in the context of illness is considered ineffective because the person fails to engage in appropriate problem-focused coping (seeking medical attention or adhering to a medical regimen) that would decrease the actual danger or damage of illness.

The challenge to health care providers is determining the adaptiveness of denial and avoidance to decide on the need for intervention. In some patients it may be better to foster these coping, while in others it may be better to encourage recognition of the problem

5.1.4. Positive /optimistic thinking Vs Pessimistic thinking

Optimism, as a coping strategy, is when taking an optimistic outlook on things, that is believing that things would be better in the future and things would work out fine (Carver et.al., 1989; Pearlin and Schooler, 1978).

The positive thinking could be also seen as extension of acceptance, since patients in this study found to make the most of his/her circumstances.

5/11 "You've got to believe and hope that everything works out, and everything worked OK. for me".

As Kubler-Ross (1969) states hope is part of acceptance. Hope equates to a feeling that suffering has some meaning and that it will pay off eventually if it can be endured a little longer.

1/2 "I'm still on quite a heavy number of tablets and I still go through the moodiness but you can only control that yourself, I mean you always look towards hoping they can manage to reduce the medication in some ways".

7/8 "I've got tomorrow to live for, that's what keeps me going".

4/8 "I feel like superman ,it's the only way you can feel".

14/1 "Every day is a new day".

11/7 "Somebody asked me what I want for my Christmas present and I said a ten year diary (laugh) I said I want to be able to fill it in every day".

7/6 "I think you've got to approach this with a very positive attitude, its a case of I'm going to walk out of it and that's the only way you don't think about what happens , I think an open mind should think that way you are going to walk out of there in a very short time, I think if you go in that way you'll come out that way".

5/10 "I don't moan and roan it's not worth, I don't worry if I die, you'll die anyway if you worry or even if you don't worry, so why to worry now-do you think I'm crazy? (laugh) you probably do, but that's my outlook on life".

As it was found in the study positive thinking was associated with adaptive outcome, that is satisfaction. Patients who tended to have a general positive outlook appeared to be satisfied with their situation post-operatively, and also tried to make the most of their circumstances, accepting problems as part of the treatment, something that would make them well. These coping skills, in turn, were found to

attribute to an adaptive outcome, that is satisfaction, and their satisfaction made them to continue thinking positively for the future.

Even though the positive way of thinking seemed to contribute to recipients' satisfaction, it seemed difficult to understand whether positive thinking caused satisfaction or satisfaction caused further positive thinking.

Taylor and Brown (1988) have suggested that positive thinking may help people profit from negative life events by allowing them to alter the meaning of the events in positive ways. Positive feedback from effective coping responses to stressors, probably also plays a role in strengthening resources. Baumann et al (1992) having interviewed 51 recipients, found that the significant negative association of optimism with symptom frequency and distress, suggests that optimism alters perception or interpretation of certain body sensations.

7/6 "I am happy and I have nae problems, everything feels the way it should after the operation...you've got to approach this with a very positive attitude, it's a case of I'm going to walk it and I'm going to walk out of there in a very short time, that's the only way you don't think about what happens if I die or....., I think if you go that way you'll come out that way. I have no, no problem and I am happy, that's the way I feel ...my life is in front of me now , I shouldn't be thinking about what's might have been or what has been, I've got tomorrow to live for and that's what keeps me going."

In research linking optimism with lower symptom reports (Scheier & Carver, 1987), being optimistic was consistent with having few symptoms. But as Leedham et al (1995) state, for heart transplant recipients it is unclear whether a positive

outlook is beneficial in situations in which adaptive behaviour is inconsistent with optimistic beliefs. Heart transplant patients need to engage in sick-role behaviour, such as taking many pills, that appears inconsistent with the belief that one is doing well.

5/3 "You always look forward you never look backwards and the light at the end of the tunnel is getting brighter and brighter all the time, you know there is no problem....It's marvelous, terrific, it's been tremendous it's been better than I could ever have imagined, I'm prepared for anything else that's going to happen because I know something, obviously things will happen and if they do I'll face them because as I say I'm fine and I always look forward never look behind."

11/7 "I'm on bonus time I've got extra now, an extension to my life, so no matter what happens to me I can accept it and I can take it no matter what illness befalls me , I've been saved so I don't have any fears if I die tomorrow I would be quite happy with what I've had, I had a year and a half of health and life. At the moment I'm getting a wee bit too happy because things are going well and I would like to see it extended. Now I remember somebody asking me what I wanted for my Christmas and I said a ten years diary and to be able to fill it every day."

Another issue raised from these findings about the contribution of positive thinking to the outcome, was the extent to which a positive way of thinking reflected a style of coping characteristic of heart transplant recipients. On a more general level, was a positive way of thinking an adaptive response to the transplantation situation, or did it represent a broader personality characteristic or attribute that heart candidates brought to the transplantation experience?

But some other patients used pessimistic thinking as way of coping.

12/5 "I don't see any point in making plans for 10 years in advance or anything like that, if I maybe plan for something 6 months from now I can guarantee you in 6 months from now I'll be ill ".

32/7 "I can't make plans for Christmas eve, I might not be here I could be lying in the hospital I canny make plans, whenever we make plans to do something , something goes wrong".

But what made the patients use either optimistic or pessimistic thinking as ways of coping?

In the following two examples, patients who appraised the heart transplant as "a second chance in life", were likely to employ optimistic ways of coping. However it seemed difficult sometimes to distinguish whether it was their perception of the heart transplant as "a second chance" that made recipients employ optimistic ways of coping or whether it was the optimistic way of coping that made them perceive it as so.

5/2 "I would go through it again tomorrow just now I really would, I don't find any problems everything is great like in the gardens rosy, but I'm prepared for everything no matter what the snag is ,because its five months since I've had the transplant or I would have been dead, so I always look forward I never look backwards and the light at the end of the tunnel is getting brighter and brighter all the time and there is no problem".

16/1 "I think it's when you waken in the morning and you just say, another day thank God, it's a bonus-I've got quite a few problems so I canny say that I am a lot better but I've still been well worth it, it's been worth it 200 times better than what I was before, but there are lots of complications caused through drugs, I've got pains in my back and chest and I take a lot of pain killers for it- but everybody, there's a lot of them have had trouble with their back- but other than that I'm fine- my legs are a little bit weak but they're getting better, you just feel you are so lucky to have to get a chance, plenty."

In the following two examples patients who appraised the heart transplantation as an "exchange of one problem with another" or perceived the problems experienced as unbearable problems, were likely to employ pessimistic or passive ways of coping. The same cyclical relationship of cause and effect that applied for the optimistic way of coping applied also for the pessimistic way of coping.

11/5 "It's been an ordeal, it's been an experience as I said if I've had a bit of hind sight I wouldn't have done it"

28/4 "And then not being able to be in control....it was out of my hands you know always sick and I thought oh this is awful I really felt one day , either cure me or kill me, because I'm so fed up feeling ill...".

The above examples demonstrated that the perception of the problems experienced might had influenced the employment of particular coping strategies and affected the outcome (as it will be discussed in Chapter 6 and in Chapter 7.1.3.1.)

5.1.5. Planning ahead/ Setting targets/Setting goals

The creation of new long-range and intermediate goals promotes positive morale and preserves the person's general sense of control and self-esteem, which, in turn, can facilitate realistic efforts to function (Rodin & Langer 1977).

15/2 "I would say more than 50% of it is attitude. It's a question of you know really setting yourself targets and goals all the time and being able to try to achieve them rather than.... I know one transplant patient in particular who is sort of went home and just sat himself down in an armchair and just letting himself go, for me its a complete waste of a transplant because he is not doing anything with his life , he should be out enjoying himself but he sits there and almost vegetates-which is sad".

Patients coped with their problems either by abandoning old goals or creating new ones.

3/9 "I'm leaving the restaurant, I've sold the house -I live in a big house now it's only myself so there is no point- I'll move to a flat and try to be stronger, that's my first priority at this stage to built myself up and get strong. And then I'm moving to where I'm going to start something but I'm going to be involved so much I'm going actually to live there I'm going actually to become part of it and I'll be quite happy because its what I've wanted to do for years anyway, and it will be helping others at the same time like a chain reaction, its literally putting my money where my mouth is right, because as I say earlier you can't take it with you. That's nice, its a super feeling its a super feeling for me because it makes me feel good, it'll make me feel good to make other people feel good".

10/6 "I just want to get fully fit and do things more things you know like when I was healthy".

11/8 "I try to set targets, plan ahead and I try to do things and prove to myself that I can still function reasonably and normally".

12/3 "I think most people who get heart transplants have got a great if you like will to live you know you've got this great desire to live, I've been lucky I've had another 3 years, I've been able to see my boys do things, most of them have now jobs, one of them got his degree and he's left University and he is very successful and the other one is serving his apprenticeship now and he is going to be successful, and before I had my transplant my goal was to see my son getting his degree and that was it I lived for that, that was a big goal he started University and the big fight was to live long enough to see him get his degree, I've done that and now I've just rearrange my goals. I've decided my new goal is now to see him getting married and the next goal is to see my first grandchild...that'll be nice".

According to Carnevali (1988), the desire to survive, to overcome, and to achieve life goals is a major resource in patient's adaptation phase with the cancer. While optimism and goal directed behaviour have not been consistently found to affect duration of survival (Cassileth, 1988), they do seem to bring other rewards, for example, fewer job difficulties (Houts, et al, 1986).

Sometimes patients have a strong desire to seize an opportunity to be different, to accomplish goals that had not existed for them before (Blum & Blum, 1988). It may be that daily living had not fully tested their resources before and they now have found capabilities and strengths they had not previously recognized (Carnevali,

1988). Similar attitudes were reported from heart transplant recipients in this study, who felt that their postoperative life was a "second chance in life".

5.1.6. Keeping busy

Many patients reported engaging in a particular hobby or in work-like activities as a way of distracting their attention from problems experienced.

15/14 "My wife and I we have a caravan we go to every weekend, I do a lot of modeling I do a lot of painting , I play bowls, I go swimming em I love walking with the dog , I have a very active life .....something to keep me going , something to keep my mind occupied. My modeling....that kept me going, that was my way , that was my therapy".

14/4 "I don't think I'll get back to work so I just do a wee bit gardening and anything I can try just to take up my time".

4/9 "I do what I feel I can do and I get told I shouldn't do this or I shouldn't do that but I feel like doing whatever I can physically achieve because the only things impaired is your legs and your arms and you haven't got the same stamina but I just do whatever I can, I'm building an extension at the moment to my house on my own from scratch from the ground up".

Some activities might needed to be abandoned because they were too physically demanding and exceeded the patients' limits. These patients needed to be encouraged to find alternatives, less physically demanding activities. This might

entailed developing new hobbies and activities or it might involved modifying previously enjoyed physically demanding activities.

15/14 "I can cope with that because I'm in the fortunate position where I've plenty of hobbies and I can keep myself occupied very easily. It must be much much more difficult for people who have no hobbies and no interests."

Distracting activities fall into three general areas: work, recreation , and social activities (Strnbach, 1987). Work includes not only paid employment, but also a variety of other work-like activities. Recreational activities can include any number of hobbies and leisure time pursuits that the person finds relaxing, stimulating, or enjoyable.

Such kind of activities were found in the study to both distract the patient from his problem and enhance his self-esteem, when he is creative.

5.1.7. Self-reliant /Need to be independent

This appeared to be a strategy developed by the patient against the pressure exerted by individuals and society in general for the patient to become dependent and to rely on others (as it was illustrated in the category of family support and role transition).

As Bailey and Clarke (1989) stated, a self-reliant individual is likely to seek to cope with demand personally and independently, whilst a person who was extremely

dependent is likely to attempt to cope with demand by seeking help from others (p.40).

37/2 "I live myself and I'm quite used to that and always managing myself. I got a daughter but I wouldn't impose on her I'd really need to be desperate before I'd ask her to give me a hand with anything, I'd normally sort things out myself any problems I had".

Patients in this study argued that whilst not rejecting help where it is needed, coping on one's own enhanced their self-respect and their self-confidence.

1/2 "I still go through the moodiness, you get quick tempered but on the whole I've controlled that , you can only control that yourself you don't need any help".

11/11 "Certainly I rallied round me. I prefer to get on myself and see what I could do and try and build from there, I found that if I knew I had to do certain things I could force myself to them and manage and cope reasonable well".

Witenberg et al (1983) found that patient causal attributions, perception of control, and ascribed meaning of their illness predict their coping and compliance with the medical regimen. They also found that patients who believe they have control over the course of their illness do better.

The notion of locus of control (Rotter 1966) is based on the belief that outcomes (reinforcements) are either due to personal factors (internality) or caused by factors external to the individual (that is, fate, chance or significant others). Several studies

have examined the moderating effects of locus of control on the stress-outcome relationship (Rotter 1966; Anderson 1977; Johnson 1978; Strickland 1978).

Strickland (1978) noted studies that indicated that people with an internal locus of control are more likely than people with an external locus of control to engage in an information search about disease and health maintenance when it is relevant to their well-being and in preventive behaviours, such as wearing seats belts and going to the dentists for check-ups. These behaviours would be classified as problem focused within the theoretical framework of stress and coping adopted. Furthermore, Anderson (1977) found that, in comparison with externals, internals were likely to employ more task-centred (problem-focused) coping behaviours and fewer emotion centred coping behaviour. Of interest also is Anderson's (1977) finding that internals whose performance improved became even more internal, whereas externals who gave a poorer performance became more external. These findings suggest that beliefs about control are reinforced by experience, as is assumed by social learning theory (Rotter 1966, 1975; Bandura 1977). The pattern seems to be self-fulfilling: the person who feels challenged generates fewer negative emotions that require attention and is therefore in a position to engage in problem-focused coping efficiently.

In a review of the literature dealing with the relation between locus of control and behaviour related to physical health and illness, Strickland (1978) suggests that internal locus of control improves health because it is associated with preventive behaviour, efforts to improve physical functioning and greater resistance to physical and psychological dysfunction. In the area of mental health, it was found that people with internal locus of control suffered less from severe psychiatric disorders (Lefcourt 1976) especially from chronic depression (Abramson et al, 1978; Solomon 1989).

5.1.8. Comparing oneself with others

Patients quite often made comparisons with less fortunate others, selectively focusing on attributes in which they were favored, or between themselves and non-heart transplant people. They often created hypothetical worse worlds with which they could compare themselves (as in the example 7/6).

What seemed to ease a patient's worries about the strain he/she put on the family was comparing the situation with something worse in order to lessen the importance of the strain.

7/6 "I definitely put a hell of a strain on the family but I don't think it would be as much strain in the family as if I had snuffed it, I think that would have been a bigger strain if I died without this transplant, it would have been a far bigger strain on the family than going through the transplant and hopefully I'll get a good 2 or 3 years ken to make up for the strain they're going through the now".

Also through social comparison, individuals can be provided with information about how others have experienced similar emotions and problems (Callan & Hennessey 1989).

23/12 "I did discuss the operation itself, I remember discussing with one person the effect of the drugs I was concerned about the steroids and the effect it was having on my body. Then I remember I was introduced to another gentleman and I was surprised and I said oh he had his transplant oh gosh I would be like him I would be up on my feet as quickly as that , and that's when I stopped worrying so much. Everybody worries about the operation but as soon as you find that its not

going to have you bedridden for months .....and there are problems but you accept them, I'm not too concerned about the side effects I know they're going to be there so I just accept them. I'm happy and everything seems to go quite smoothly. I like talking to other heart transplant fellows because we are giving each other support, chatting away and letting them know that things aren't all that bad, I suppose like every other unit we have had a few deaths here but people have died going to the dentists and there is nothing to do about that. In fact I tell people that I maybe in a better position than most people because I'm being tested every 3 months and they can tell you if its all right and if not they can do something about it, but some people who think they're fit never see a doctor from one year into the other and they could well be in a quite a bit of danger from either heart disease, cancer or anything like that but I'm seeing somebody every 3 months, I'm in a unique position."

5/7 "Sometimes talking with other heart transplant patients gets me down, they moan and groan and there's people been done years and they still moan and this is all wrong because they wouldn't be here. Some people can't accept that, they imagine that you get a new heart and you just go out and start running marathons and nothing else happens but I'm prepared for anything else that's going to happen. I know something, things will happen and if they do I'll face them because as I say I'm fine once I lie here. Always look forward, never look behind you look behind and you are dead, never be frightened and believe in the Lord and you'll get places".

As was found in the literature (Pearlin and Schooler, 1978; p: 6), one frequently used coping mechanism, which function to control the meaning of a problem, involves the making of positive comparisons; a device captured in such idioms as

"count your blessings" or "we are all in the same boat". Thus conditions appearing to an outside observer as very difficult may be experienced by people as relatively benign when they judge the conditions to be less severe, or no more severe than those faced by their significant others. Comparisons may entail a temporal frame of reference as well one formed significant others. Thus, is hardship is evaluated either as being an improvement over the past or as a forerunner of an easier future, its effects will be tempered.

9/2 "Also chatting to your fellow transplant patients helps a great deal. And you discover what they've got wrong you've got as well, where inside you were thinking its only you that's like this and you worried what's going to happen next, and its when you get talking to other transplant patients you hear them and its working, because they are going through exactly the same as you and it makes you feel better if you have a wee chat with them".

1/2 "My health is reasonably good I don't think I have near the problems that other people have that's been through the same as I have".

Wills (1981) notes that "downward comparisons" may be a useful way of bolstering self-esteem in the face of threat and Taylor (1983) observes that patients may maintain self-esteem by seeking positive differentiation between themselves and other patients who they regard as worse off, or coping less well. Adapting to the consequences of illness may therefore depend upon being able to regard ourselves as "well off" in comparison to others. Perpetually comparing ourselves with others who we regard as more fortunate is likely to result in lowered self-esteem and impaired coping. Taylor also points out that overly optimistic, internal attributions of control and expectations regarding present and expected improvements may play an

important part in successful adaptation to illness. It seems that optimism, rather than realism, about ourselves and others' perceptions of us is the key to optimum psychological functioning (Abraham & Shanley 1992).

Some patients also found that comparing themselves with others was not so helpful.

11/9 "I have got two close relatives that have had heart bypass operation and they made matters worse for me regarding the fact that I had to take all these nasty drugs where they didn't and they got a bypass operation that its easy and they didn't as many problems as after the transplant. They made me feel pretty awkward that I was maybe not accepting that they recovered so quickly, its now nearly a year and a half and I'm now just getting out the woods and some of them were OK after two or three weeks after the bypass operation, their would healed up and a wee bit physiotherapy and they were back at work or whatever. It's been a year and a half and now I'm starting to get there but I'll never be as good as they were because of the depending on the drugs".

3/2 "I've made some silly mistakes, stupid mistakes by getting advises from people who were in and had their operation....it was nothing like what I was going through. They were saying well, this will happen, that might happen and it didn't, that what was happening to me was totally different from what happened to them because each person is an individual, you can't sort of put them together into boxes and say well you are going to act like this, everybody is different, and I found out quite quickly that nobody acted the same, I was getting symptoms that nobody even had though about".

Comparing oneself with others, either real or imaginary, in a similar situation, in order one to evaluate the situation, was discussed in the literature (Pearlin and Schooler, 1978; Moos and Billings, 1982; Taylor, 1983; Taylor and Lobel, 1989;).

Whether the employment of a particular coping strategy would be proved useful or not, leading to satisfaction or dissatisfaction, seemed to depend on other factors as it will be discussed in 5.2.3.

5.1.9. Making attributions

The attributions people make regarding the causes of their illness are related to the topic of control over health outcomes. In a study of people who were paralyzed following accidents, Bulman and Wortman (1977) found that positive coping and efforts toward rehabilitation were associated with blaming oneself for the accident. The authors suggest that self-blame may be adaptive because it is associated with perceiving events as under personal control. However, Bulman and Wortman cautioned that under circumstances in which events are not subject to personal control, self-blame may be maladaptive. This kind of self-blame has been implicated as a component of depression (Beck, 1976; Janoff-Bulman, 1979) and a depression related attributional style is not expected to predict good adjustment. Witenberg et al (1983) found that in truly uncontrollable situations, self-blame may be detrimental if it leads to attempts to modify the unmodifiable. It may interfere with an acceptance of circumstance, and also with living a life as usual.

Patients quite often seemed to be disturbed by the question "Why me". They might had blamed their own past wrongdoings (24/8), their heredity (3/4), the doctors or the hospital staff (11/10) and thus found a target for their pend up anger.

24/8 "I'm paying the price of being a bad boy all my years".

As Frankl (1963) has noted, people search for philosophical, religious, and personal reasons for suffering. Indeed, the seriously ill and injured typically go through a phase of questioning "Why did this happen to me?" (Kubler-Ross, 1969). Bulman and Wortman (1977;p:360) found that 28 of 29 accident victims had various explanations for the accident: God (e.g., "He is trying to help me learn about Him"); predetermination ("Things are always planned before your time"); and probability ("Things were going well, so the odds were that something bad would happen") were typical responses consistent with the idea that people search for order or meaning in the face of adversity.

33/9 "I'm not particularly a religious person but I do believe that there is a higher being somewhere what it is I'm not sure its very easy to say you believe in God but I certainly believe in something and there must be a reason, there's a reason for everything in this world I firmly believe that there is a reason why I've gone through what I have done and come out at this end , there must be a reason and maybe eventually it will be unfold to me."

Some patients tried to attribute the changes to other factors, outside of the heart transplantation, as in the following example of the ageing process.

4/1 "My mental attitude changed.....I seemed to be less tolerant now....small things like the matrimonial side of it irritates me more than they normally would.....but I don't know whether this has to do with the transplant or just with the ageing process".

For other patients it was easier to believe that their heart problem was an inherit problem.

3/4 "I know why this is happened to me, my father died and on his death certificate has cardiomyopathy he wasn't hard drinker he wasn't a drinker at all mine was aggravated by drink, but I think this problem with the heart runs on the male side of the family".

Witenberg et al (1983) also stated that, associated with the concept of control and causality is the somewhat more metaphysical question, "Why me?". Those who were unable to identify any reason for their suffering yet had thought about it rated as coping and complying poorly. By providing oneself with a reason, any reason, the individual permits himself or herself to retain the belief that there is an association between events- the world is orderly whoever or whatever controls it.

5.1.10. Blaming others

Blaming others appeared to be a coping strategy used by some patients who were trying to find a reason for their suffering.

10/3 "It was 4 years ago I was quite bad I should have had the operation then I don't know why they never put me forward for it , my own doctors they should have

done that years ago when it was got diagnosed, it was a big mistake, I should have had a transplant , I should have been put on the list. As now I never had any time to think about it you know I came in on Wednesday and Saturday I woke up and said oh where am I, intensive care so I was just over and done and it was then when I found out that J has left me. I think the nature of the disease should be explained more to the patients and the partner. J. didn't know what was going to happen, she didn't understand and she was never told anything, things should be explained in more details ".

11/4 "I blame her (his wife) for the whole thing, I had very bad support..... that only added to my problems and subsequently I ended up in here".

22/4 "I just felt everything was going back the way they were but they didn't seem none of the nurses seemed to be bothered about that , I felt if at least I had been warned about it that this could happened but I just wasn't warned the way you could go down depression wise".

11/10 "I think some of the nurses are not very caring upstairs, they treat everybody as everybody's the same, as soon as you get up in the morning they want you to jump and get about your business and they don't seem to be too considerate as regard of how much pain you are in. I was quite angry within myself because I know I can suffer pain and they were making out that I was being maybe a bit childish or tot tolerating the pain , and it was very acute what I had with my chest, I think it was them that couldn't accept or come to terms with the fact that I did have a problem, and that made me angry".

5.1.11. Acquiring social support

As patients experienced the stress that accompanies heart transplantation, they attempted to cope by seeking various kinds of support from their social network (as it was illustrated in 3.4.1. and in 5.2.3.).

According to Abraham & Shanley (1992) people's individual ability to mobilize social support also determines how much he/she receives. People begin to learn support-seeking skills in infancy and people who lack appropriate communication skills or who have learnt to be self-reliant or resigned to helplessness receive less social support than those who actively seek information, advice and emotional support.

Social support is increasingly seen as psychologically complex. Wortman and Dunkell-Schetter (1987) identified several types of support. They include expression of positive feelings, including indications that one is cared for or held in high esteem and, the expression of agreement with or acknowledgment of the appropriateness of one's beliefs and feelings. Invitations to disclose and discuss beliefs and feelings, offers to advice and information or access to new information sources are also forms of social support. These types of support may be vital to the establishment of a helpful relationship, whether this is a friendship or a professional counseling relationship (Shanley & Abraham 1992).

As Lazarus et al (1981) state, the important distinction to be made is between the number of relationships a person has and the person's perception of the supportive value of social interactions. The former is usually referred to as the social network; the latter, as perceived social support. The benefits of social support are assumed,

not measured, in the social network concept, while in the concept of perceived social support an effort is made to assess the person's evaluation of the supportive quality of a relationship.

Individuals with high levels of perceived support appear to be more resistant to the adverse psychological effects of environmental stressors than do individuals with relatively low levels of perceived support; that is, perceived social support may buffer individuals from the adverse psychological consequences of exposure to stressors (Lepore et al, 1991).

Bordow & Porritt (1979), Packa, (1989) and Spiegel et al (1981) produced evidence to show that the maintenance of a person's physical and psychological well-being is strongly influenced by the social support receives.

15/10 "If you are lucky enough to have friends, friends are great help friends tend to be there all the time.....I always say that the three "F"s family, faith and friends were the 3 things that pulled me through."

38/9 "The nurses they're interested in their patients in a sense that they'll sit and listen to you, they are listening to you if you just want a blather, and a lot of times its better than getting a tablet just sit and talk to somebody-for that reason I'm not frightened because they have a very calming way. Standing there holding your hand reassuring you , and this was great , great help , they help you to reassure you and take your doubts away".

Unfortunately despite the evident importance of social support people who fall ill may actually receive less support from family members and friends (Wortman & Conway, 1985).

Heart transplant patients often admitted avoiding contacts with people in the fear of an infection.

39/8 "I feel just now I don't really want to catch any infections if possible, especially the flu because even before I had the operation the flu I took was very badly so I'm kind of keeping away from as many people as possible".

The absence of social support can be seen, according to Brewin (1984), as a vulnerability factor shown to be relevant to a wide range of physical and psychological disorders. Although this is normally considered as a social variable, absence of support may in some cases be related to cognitive characteristics of the person. For example, people who have low expectations of being able to form relationships, who do not expect others to be supportive, or who believe that others are unlikely to understand the unique nature of their problem, may actually avoid potential sources of support.

11/11 "I lost a lot of friends and that's hurts me quite a bit. It's very common in this area I stay when there is an illness , serious illness in the family like that, that people stay away, if you've had 100 friends you'll lost 95 and some of the 95 you lose you would bet that some of them are your closest friends, people that I knew for a long time 20-30 years. I don't know if this is common think but it's pretty common here and you could be left pretty bored a lot of the times, I don't go out socially I stay in, I don't have any social life....".

According to Kessler et al (1985), the severity of the recipient's problems, as well as his or her ability to cope with these problems, may also determine the amount of support received. There is evidence from the social psychological literature that people are often threatened and made uncomfortable by those who have experienced a life crisis, particularly if they feel vulnerable to a similar fate. For this reason, the more severe the victim's problems, the more threatened, and therefore unsupportive, others may become. This suggests that those in greatest need of social support may be least likely to get it.

Other patients also described a wish to avoid association with other transplant recipients and visiting the hospital because the death of a transplant recipient posed a threat to the stability of those remaining.

31/2 "I've got very very friendly with another transplant patient and he died, I don't know whether that is the reason but I don't particularly like coming to Glasgow and when I come to the hospital everyone's very nice and all very civilized but I do find it eh..... I don't like it at all and if I can find half an excuse not to come up here I'll do it".

According to Packa (1989), social functioning is an area in which nurses can assist recipients and families in further improving quality of life (QOL) after transplant. For example, recipients may fear that causal acquaintances will feel uncomfortable near the recipient. Recipients need to be encouraged to discuss such fears as this prior to returning home, and nurses could assist recipients in management of these fears by identifying plausible responses for recipients to use in such a situation. Recipients may also believe that social encounters are a source of possible infection and so may remain in a small, safe circle of relationships.

Recipients need, as the time after transplant increases, be given additional support and encouragement to increase social contacts to continue the improvement of their QOL. Social contacts may have diminished during the prolonged illness prior to transplant. In these situations, recipients and families need sufficient encouragement to develop new friendships or rekindle old ones that may have waned. Increasing social involvement may contribute significantly to improvement in QOL.

5.1.12. Talking about the heart transplant experience

Patients often expressed a need to talk about the heart transplant experience and to share their thoughts and feelings with family members, friends or other heart transplant fellows.

4/4 "I'm pleased to tell people about it and I like to extol virtues of what you know the minimal service and all the doctors have done for me".

1/7 "One thing that stand out in my mind, and I want to tell everybody is that the care and the attention you got in the transplant ward it was second to none".

4/4 "I'm too pleased to tell people about it, the first year after you get the transplant particularly the first 6 months you actually want to get in a crowd and shout about it and tell people what is happening to you, but as it goes on you just accept it and it's not always forefront of your mind, I've now got 3 years behind so its always in your mind but it's not to the fore where you would like to tell everybody you meet what's happened to you, it's maybe sort of a childish attitude where you want to shout about it but so tempers off as you go on.....I don't do that

myself now but in the past you always like to point it out to people who didn't know about it".

14/1 "The problems I have I just usually talk it over with the wife and don't bring anyone else into it, just tell the wife, talks it over, I don't need to go to any of my family"

To the question "Do you like to discuss with the other heart transplant fellows?" there were a number of reactions.

4/5 "Oh yeah it's a common subject because we don't know everybody's background so there's always going to be a conversation like with yourself, there's always got to be a common ground and we always ask how are you getting on and did you have any problems you know any rejections or the usual link between the lot of us, well it helps you to make conversation, other than that you haven't got any other means of conversation unless you ask about the family but you don't know about their family, their work, their hobbies because you're not in contact daily or weekly".

14/1 "We've actually helped the chaps who came for evaluation by sitting talking to them which we thought was a good thing, sort of handed you down and said what his problems....we put their minds at ease which helped them quite a bit".

Contact with previously operated individuals might be of help, as patients who have successfully made this transition provided good role models.

9/2 "Also chatting to your fellow transplant patients helps a great deal. And you discover what they've got wrong you've got as well, where inside you were thinking its only you that's like this and you worried what's going to happen next, and its when you get talking to other transplant patients you hear them and its working, because they are going through exactly the same as you and it makes you feel better if you have a wee chat with them".

But some patients believed that by talking to other heart transplant fellows might influence people waiting for the operation in a negative way:

11/12 "Yes we swap symptoms and pains and you find there are a lot of similarities between different patients, but its maybe bad in the respect of influencing people that waiting to get the operation, and maybe they should have them on different days because you may upset somebody if you say about having a problem. They're no looking for any problem but I'm pretty sure their ears will be picking up all the chat that's going about, and I can say that I've had that pain and you say to other people have you had such and such problem and you start discussing each others the whole thing right through and I think you can pick up pains off other people you don't actually have by talking about them".

11/12 "You get quite close actually to the other patients that are in the ward at the same time as you, no brotherly or sisterly but pretty close and its quite upsetting to find that somebody's having a problem and might have to come to the hospital to get more treatment, and the whole thing is very tiring, very tiring experience"

Some patients did not like to talk to other heart transplant fellows. Sometimes patients preferred to keep their feeling "bottled up " and withdraw from social interaction.

2/7 "I don't express my worries enough, if I worry I don't let other people know that I worry, I don't tell anyone in the family , I wouldn't tell my friends that I'm worried, I think that's probably why I've got high blood pressure but I just keep everything to myself and I wouldn't tell my friend or my sister that I'm thinking of rejection, I try to convey a public image of everything being perfect, I might tell them after when something has been diagnosed".

6/5 "I think I would tend to keep things to myself actually, I'm one of those who before my operation I didn't discuss with anybody or let it be known that I was going for a heart transplant, I think the reason is that everybody starts giving you sympathy...".

5/7 "Sometimes they get me down really because they moan and groan and there's people been done years they still moan and groan and all this is wrong. I mean they wouldn't be here some people can't accept that they imagine that you get a new heart and you just go out and start running marathons and nothing else happens and this is wrong, and upset me".

7/5 "No I think the worst thing you could ever do is talking with that lot. Doom and gloom merchants , they sit there and they think the worst things that they could possibly think of, and then some poor bugger just went through and they try to frighten the pants off him, I was sitting there and I couldn't tell you what some of them say, I just switch off completely. I don't want to ken about their problems their

rejections, so if somebody comes in and say you are getting fine that's the body I'll listen to, you get these dooms and gloom merchants Christ the winds, they moan all the time about the food and such like and that's nae way to approach the job you are doing".

Talking it out was described by Cooper and Faragher (1993) as a coping strategy. Many people relieve tension by talking it out. Talking implies establishing and maintaining a contact of sorts with another human being. In addition, it enables new ideas to emerge and new perspectives to be entertained. This way coping may be seen as the medium of a therapeutic intervention. This finding may has profound implications for nursing because nurses are the health care providers who spend the most time with patients.

5.1.13. Seeking spiritual support

According to Kemp (1995), spiritual needs include the search of meaning in one's life, hope, and relatedness to God. Fulfilling spiritual needs aids in alleviating expression of distress. As was found in this study, spiritual faith helped recipients to cope with the emotional distress involved in heart transplantation.

9/2 "My faith in God helps me, my faith is much stronger now, I go to church often and I get a lot of help from the church".

6/4 "I'm sure God pulled a few strings for me to find a heart for me otherwise I wouldn't be here today".

5/6 "Always believe in the Lord and he'll help you don't worry as long as you've got your belief and I've got my belief and the belief was that when I was going for the operation made me believe that I would do it and get through it".

12/4 "I think if you've got a wee bit of religion of any kind you use it as a crutch at a time just to help you a wee bit. But being a Catholic, I don't know if non Catholics or Atheists how they would feel but I would imagine, having your own religion that would support you, but I don't know how people who haven't got any how they would handle it, its a crutch".

15/7 "One very very strong factor in my recovery , I don't know if I could have come through it without my faith.. that sort of pulled me through.....if you have a strong faith then its just that you know that he is there anyway so all you have to do is speak to him....And when somebody asked me why this is happened to me I said why shouldn't have happened to me because I'm better equipped to handle it than somebody who hasn't got faith. And then somebody asked what if when you die there is nothing and my answer to that is well fair enough if there is nothing then I won't have lost anything , my life has been all the more rich because of the fact that I believed there was something, and if there is something there fine I'll wave to you when I'm going down".

According to McCrae and Costa (1986), *turning to religion,* as a coping response may be quite important to many people. One might turn to religion when under stress for widely varying reasons: religion might serve as a source of emotional support, as a vehicle for positive reinterpretation and growth, or as a tactic of active coping with a stressor.

However, the relationship between religion and psychological well-being is not yet clearly understood. Findings have suggested that significant religious involvement can be a positive correlate of normal personal functioning (Bergin et al, 1987; Spitzer et al, 1995), but the explanation for this relationship remains unclear. In addition, it has not been established whether religion has an impact on well-being through coping.

5.1.14. Changing priorities and perceptions.

Patients often used skills aimed at altering values and priorities in line with the changing reality, in order to minimize the aversive aspects of stressful events and help promote adjustment.

2/5 "I think maybe is just the trauma of the operation, the fact that you are so close to death and you realize that the perception of priorities changed and you become aware that some things are more important than others. I think that's what produces the emotional reaction now. I've probably taken the relationship with my family for granted for many years, we'd all grown up together and nothing really changed in many years whereas all of a sudden now I am seriously ill and my family have come in to help....and I feel very protective of my family now".

Some patients often tried to give priorities in other aspects of their lives, outside the heart transplant experience, and to emphasize some desirable trait in order to minimize the stress caused by their transplantation.

3/4 "I'm going through a divorce right this is before my transplant -I'm getting divorce in February that is finished, its a miracle and I have a daughter- I just think about things, a lot of things have happened to me and they are all sort of grouped together and with having the transplant its like another bind but I've been very lucky and I have my own business I have a restaurant . I've been very lucky I've travelled a lot round the world-I'm good at my job I mean nation-wide you know television, newspapers, lots of awards , I won the Chef of the year".

This coping strategy in the above example was described in the literature (Pearlin and Schooler, 1978), as *selective ignoring*: a device that functions to control the meaning of a problem. Selective ignoring is typically attained by casting about for some positive attribute or circumstances within a troublesome situation. Once found, the person is aided in ignoring that which is noxious by anchoring his attention to what he considers the more worthwhile and rewarding aspects of experience. One's ability to ignore selectively is helped by trivializing the importance of that which is noxious and magnifying the importance of that which is gratifying.

Devaluation of money as part of changing priorities was found to be very common in heart transplant population.

3/6 "I have become more tolerant after the transplant, life is too short, there's no point in moaning about things that I would, my priorities have changed totally, I never put too much importance on money, now it seems lees important than what it was, you canny take it with you, I could have been six feet under in a box.....I've got things I'm going to do now that I would never dreamed to have done. I look at things different-open my eyes a bit and take my time- I take my time maybe, that's

one thing I've had to do as well physically because I've slowed down-its amazing what you can see when you slow down and open your eyes".

2/8 "I have no financial worries at the moment and it's easier for me to cope because I don't worry about money.

Devaluation of money, and *selective ignoring* (as described previously), involving hierarchical ordering of life-priorities, were described in the literature (Pearlin and Schooler, 1978) as devices to control the meaning of the problem. In hierarchical ordering, people are attaching a differential importance to different areas of their lives. They may succeed in avoiding stress to the extent that they are able to keep the most strainful experiences within the least valued areas of life. When confined to life-areas defined as of secondary importance, strains are less likely to result in stress because they are less likely to threaten the self. The hierarchical ordering can, thus, function to shrink the significance of problems and, in this way, minimize the resultant stresses.

According to Lazarus (1966) in circumstances where coping does not succeed in changing or eliminating the problem may be buffered by responses that function to control the meaning of the problem, that is, the indirect coping. The way an experience is recognized and the meaning that is attached to it determine to a large extent the threat posed by that experience. Thus the same experience may be highly threatening to some people and innocuous to others, depending on how they perceptually and cognitively appraise the experience. By cognitively neutralizing the threats that one may experience in life situations, it is possible to avoid stresses that might otherwise result.

5.2. Factors influencing the coping process

It was found in the study that heart transplant recipients' cognitive appraisal, definition of the demands involved, and selection and effectiveness of relevant coping strategies were influenced by other factors. These factors, described below, were classified as personal, illness-related, and social factors.

5.2.1. Personal factors

Personal factors influenced patients' perception of the demands during the post-transplantation period and consequently their coping.

5.2.1.1. Values in life (education, family, relationships, grandchildren) and value on life (the importance of life and consequently the importance of being alive).

Values in life and value on life, were not mentioned previously in the literature as personal factors influencing the coping with the heart transplant. The values patients had in their lives, for example the importance of education, of good family and social relationships, of marriage of their children and getting grandchildren, and faith in God, were found to play an important role in influencing their way of coping. Values in patients' lives seemed to enable them to create meaning out of life, even out of damaging experiences, and to maintain hope. The value they put in life and the importance of being alive was understood to play an important role in patients' acceptance of problems and their degree of satisfaction.

A range of personality characteristics including values, commitments, goals and beliefs about oneself and the world, helps to define the stakes that the person

identifies as having relevance to well-being in specific stressful transactions (Folkman & Lazarus 1986).

9/2 "You take these things as they come and accept them and just get on with life because you are still living and I've got grandchildren along the road that I would never seen if I didn't have my transplant. I feel good now, life's good now and I don't suppose I'll get any better than what I did. I also found that I'm a lot more cheerier person and got a more jovial personality to that what I had before maybe that's because you've got a second chance at life that makes you see the funnier side of things that I never seen before. The simple things in life like the birds, gardens, flowers, nature I get a lot of pleasure from that, I mean that I feel that more now. I think I'm also much easier pleased about things than what I would have been before. I've changed quite a lot and probably for the better-I'm more more thoughtful towards about my husband about how he is sleeping, is he depressed or anything".

2/5 "I think the basic thing that has changed is the emotional part, I'm much more aware of my emotions , I also demonstrate my emotions much more and it's much less likely to worry about what other people think about me. I demonstrate my emotions publicly much more than I did before, I'm not a cold person but I would sometimes get frustrated in public .....probably it's the case of being alive, the joy, and the alternative to sitting here now than to be 6 feet under and that makes you feel quite happy."

The above example shows how the importance he was giving to the fact that he was still alive (value on life) could affect his coping (changing perception) and also affect the outcome (satisfied-happy).

12/3 "I think most people who get heart transplants have got a great if you like will to live you know you've got this great desire to live, I've been lucky I've had another 3 years, I've been able to see my boys do things, most of them have now jobs, one of them got his degree and he's left University and he is very successful and the other one is serving his apprenticeship now and he is going to be successful, and before I had my transplant my goal was to see my son getting his degree and that was it I lived for that, that was a big goal he started University and the big fight was to live long enough to see him get his degree, I've done that and now I've just rearrange my goals. I've decided my new goal is now to see him getting married and the next goal is to see my first grandchild...that'll be nice".

The previous example could be interpreted in that the value one places on things in his life, may play an important role on the way he copes with the transplant experience. The importance of education, marriage of his children and grandchildren, as values in his life, seemed to play an important role in helping the patient to cope as he rearranged his goals and he found meaning in his life.

5/1 "You take your time and let everything work itself and there won't be any problems. Sometimes you jump up quick and your heads spinning and you are a wee bit breathless because you forget the fact that you've had the transplant and then you realize oh wait a minute and once you take your time everything will fall into line. It's marvelous , terrific. But there were times when you don't feel too good you know you don't feel marvelous everyday there's days you get up and you don't feel too good but you just relax maybe you've done too much the day before you know because you tend to think oh this is marvelous and you do that but you cannot you are going to just call a halt at sometimes. As I say you take everyday as it comes and every time you open the blinds in the morning and see the day and smell

the roses that's when you know you are living that's when you know it was worthwhile really yeah."

From the previous example it was understood that the patient's satisfaction was influenced by his way of coping (acceptance) and his personal characteristics (value on life). How the patient coped, accepting the restrictions imposed after the heart transplantation as part of the treatment, and the importance and value he was giving to life, seemed to play an important role in his satisfaction.

According to Lazarus and Folkman (1984), commitments and beliefs are two personal characteristics that are important determinants of appraisal. These variables influence appraisal by 1) determining what is salient for well-being in a given encounter; 2) shaping the person's understanding of the event, and in consequence his or her emotions and coping efforts; and 3) providing the basis for evaluating outcomes. The authors state, that the most graphic illustrations of the motivating property of commitments are found in cases of life-threatening illness. The "will to live", for example, is often seen as critical for survival. The particular commitments that form a will to live vary from person to person. In one it may be a commitment to one's family, in another to unfinished work, and in still another a desire to "beat the odds". The commitment to life is sometimes evident in the patient's willingness to undertake aversive treatment regimens.

The centrality of commitments in psychological well-being has been discussed extensively with reference to bereavement (Bowlby, 1973) and depression (Klinger, 1975,1977) and is a major focus of traditional psychoanalytic therapy. The purpose of such therapy is to resolve inner conflicts that impede the formation of commitments to family and work. The assumption is that the person who can make

commitments will have a meaningful and productive life (Lazarus and Folkman, 1984).

Moos (1984) states that life events are imbued with meaning by relatively stable features of personality and by an individual's unique set of obligations and beliefs. Patterns of commitment help to define which events are stressful, whereas beliefs about personal control, religion, and the role of fate or change in human affairs alter the appraisal of an event and the choice of coping strategies.

The findings of this study are consistent with these and other findings such as Duitsman et al's (1993) conclusion that patients' attitudes and will to live greatly affected the outcome of the treatment of life threatening illnesses.

The strength of commitments and values in recipients' lives were found in this study to play an important role in impelling a patient toward a course of action aimed at reducing threat and helping to sustain coping efforts in the face of demands.

5.2.1.2. Expectations.

Realistic and positive expectations or unrealistic and negative expectations were found to influence patients' appraisal, coping and adjustment to the heart transplantation postoperative life. Those that often reported that they expected that the heart transplant would cure all the problems and expressed the belief that life after the operation would be "bed of roses" or "run marathons" found it hard to cope with the fact that they still had to face considerable problems. Having high and unrealistic expectations, made the coping process and the adjustment difficult. On

the other hand, patients that expected to have some kind of problems post-operatively as part of the treatment, were ready to accept them as normal, and admitted satisfied with the fact that they still alive and were capable of solving any kind of problem.

5/4 "You always imagine that obviously it's a major operation and it's going to be difficult, and you always expect pain and you expect more pain than what I did, I expected more pain and I never got any and I didn't need any pain killers, it was just terrific."

As found in the literature (Stimson & Webb, 1975; Fitzpatrick et.al., 1984), the degree of satisfaction expressed by a patient is largely influenced by his or her initial expectations. As Stimson and Webb (1975) state, expectations may refer either to hopes and desires for what ideally should happen or to guesses and predictions of what is likely to happen. Giving information to patients as to what to expect after the operation and what side effects are likely to occur, can help patients to develop realistic expectations.

35/1 "I found it quite frustrating at first you know to get back to fitness and health....I thought getting a new heart I would be jumping out of bed doing great things ...it took a while...quite a bit of hard work, a lot of exercise walking".

28/1 "I don't think anything can prepare you for how you are going to feel we keep being told and we know that we're individuals but I couldn't imagine how I would really feel eh I thought the operation itself was the big thing and if I got through the operation I would be fine but I don't think that I was prepared for what

might go wrong or the medication just a lot of things that did happen, I suppose I was unfortunate".

The literature suggests that positive expectations predict appropriate psychological adjustment in some groups (Scheier & Carver, 1992). Positive expectations have been linked with future good physical outcomes in various populations, including, heart surgery patients (Scheier et al, 1989), recovering alcoholics (Strack, Carver, & Blaney, 1987), women with abnormal Pap smears (Antoni & Goodkin, 1988), and the large number of patients who have demonstrated the placebo effect in clinical drug trials (Taylor, 1989).

Some writers have speculated that positive expectations may contribute to negative outcomes in the long run for some people. For example, in situations in which the person has little actual control, positive expectations and their concomitant feeling of invulnerability may make adjustment to future negative events (such as worsening illness or further victimization) more difficult than if the person never expected positive outcomes (Tennen & Affleck, 1987). Thus, if highly positive expectations later meet with discouraging experiences, decreased emotional well-being may ensue. Notably, few heart transplant recipients have predictable, uneventful recoveries. Most experience postoperative complications such as infections or rejection episodes. In few other illnesses there is the potential for high optimism combined with such a high likelihood of unpleasant feedback as in heart transplantation.

Thus, it is argued in a study by Leedham et al (1995), that although positive expectations appear to be salutary, perhaps those patients who expect the best may also tend to distort reality and deny the gravity of their situations.

In the above study of patients' perception of how they experience problems (Leedham et al, 1995), one could argue that what the authors call "gravity of their situations" to be the authors' own perception of these situations. What authors perceive as "gravity of their situation" might be understood as a "blessing" for patients who see the heart transplant as an escape from death and the only chance to gain longevity. Denial of the gravity can be seen as an absence of gravity in patients' minds accordingly to patients' perception of their situation. Instead of seeing patients as distorting reality or denying gravity, one can see just patients expressing their satisfaction, admitting of not having any problem, as result of their positive way of thinking.

In summary the crisis of illness may require a change in expectations for the member who is ill, or for the family unit (Mechanic, 1974; Udelman & Udelman, 1980). Fife (1985) stated that, as the view of life is gradually modified, the patient engages in actions to adapt to the changes brought by the reality of a different life. Patients' perception of the situation and the management strategies they choose influence the process of coming to terms with the new definition of reality. The patterns of behaviour may represent efforts to protect themselves from the continual unpredictability, and these behaviours may require drastic and long-lasting modification in roles and expectations.

5.2.1.3. Previous coping experience.

It was found in this study that the nature of previous experiences in patients' lives and the coping adopted to deal with these experiences, might influence the current choice of coping strategies.

Patients who had faced problems that were very traumatic in their lives, may apply learned strategies in coping with the demands and the problems that accompanied the heart transplant experience.

3/9 "I lost a boy, I lost a son when he was born and its important to me, that was a hell of a time. I am also going through a divorce ...but I have become more tolerant, life is too short and there is no point in moaning about things , my priorities have changed totally, I look at things different."

For this patient the fact that he had faced quite traumatic experiences in his life made him to be stronger and well equipped to deal with problems in comparison with other patients. He was more prepared now to deal with problems as he accepted problems that accompanied the transplantation (*"I had a lot of problems I was very ill but then I thought well that's me through the first hurdle, the rest I'll take as it comes, life is too short and there's no point in moaning about these things."*) and he was optimist making plans for his future *("I've got things I'm going to do now that I would never dreamed to have done, I look at things differently and I'm quite happy because what I'm going to do it'll be helping others.....I'll take every bit of luck I can get but its definitely is going to work whether I've got the luck or not, and that's super feeling and it makes me feel good.")*

For some other patients, problems caused by the heart transplantation were allocated a position of less importance and were perceived to be minor in comparison with more serious previous experiences.

16/2 "I've got a hectic life. I look after my daughter , my daughter's got that M.S. and she is disabled, you know I don't have time to thing about myself, she keeps me

busy, my daughter that's the only thing that is important to me nothing else, heart transplant is nothing in comparison with this".

39/1 "I've already had an operation eh a by-pass operation so I had an idea what was going to happen. Eh the heart transplant operation was really nothing it was just after it you know I had a wee bit more pain more than the usual with going through a second operation".

Burgess & Holmston (1979) found that women who had experience the loss of a parent, spouse, or child through death, divorce, or separation recovered significantly more rapidly from rape than women who had not been through such an experience.

It seemed that subsequent coping would be facilitated or hindered by prior coping efforts. However more research is needed to clarify whether coping with one problem imparts insights or skills that can be useful in dealing with other problems, and to offer an understanding of the conditions under which subsequent coping would be facilitated or hindered by prior coping efforts.

5.2.2. Illness-related factors

The illness-related factors influencing coping, were classified as the present state of the illness and the previous illness experience.

5.2.2.1. Present state of the illness.

The health status of the patients during the period when the interviews were conducted, seemed to influence patients' appraisal of the situation. Patients who were experiencing problems due to the side-effects of the medication or complications at the time of the interview appeared to be less satisfied than patients who were free of these problems during the interview.

13/6 "You picked me in a wrong day, I had a biopsy yesterday and I'm rejecting, I used to be the most optimistic patient here in the clinic, very happy with the way things were, but now everything is seems oh! something but not right , everything seems awful !".

The physical and psychological impairment, as reported by the previous patient, seemed to reduce the ability of the patient to cope and made adjustment poorer. However, in this study, the person's level of anxiety or pain during the interview it could be seen that only had a temporary effect on the way the patient saw his/her situation. At other times the patient might had expressed different views.

These findings found support in the literature. Zumbrunnen (1989) notes in his study about coping with heart transplantation, that the severity level of physical illness appears to have a major influence on coping outcome, both before and after transplantation. The more a patient is tired, exhausted and breathless due to cardiac failure, the more the repertoire of psychological coping mechanisms appears limited, and seemingly of limited efficacy. Often these patients are severely depressive and anxious.

5.2.2.2. Previous illness experience

Patients' severity of illness prior to heart transplantation was found in this study to play an important role in patients' way of coping post-operatively. Some patients who were seriously ill prior to the operation were not able to prepare themselves for what was to happen and they were found to be distressed, anxious, disappointed and not rarely depressed, when they faced the first side effects of the medication, as a result of failing to develop realistic expectations.

35/1 "I found it quite frustrating at first you know to get back to fitness and health....I thought getting a new heart I would be jumping out of bed doing great things ...it took a while...quite a bit of hard work, a lot of exercise walking".

The severity of the trauma and impact of the procedure were experiences that were difficult for some patients to anticipate or even to understand despite being given detailed information by the nurses and the doctors prior to the operation.

28/1 "I don't think anything can prepare you for how you are going to feel we keep being told and we know that we're individuals but I couldn't imagine how I would really feel eh I thought the operation itself was the big thing and if I got through the operation I would be fine but I don't think that I was prepared for what might go wrong or the medication just a lot of things that did happen, I suppose I was unfortunate".

Some patients reported that the shock and confusion created by the initial diagnosis appeared to block their understanding of necessary information. Some

other patients admitted that prior knowledge of transplantation and the hope it offered, however, often inhibited understanding of the transplant limitations.

On the other hand some seriously ill patients prior to the operation, were found to be very satisfied with their health status following the operation as their health had significantly improved. Comparing their postoperative health with their health prior to the operation, made them happy when they realized how much their health had been improved. They understood the beneficial effect of the transplantation and they reported experiencing an improved quality of life.

5/3 "Beforehand you don't look forward to days because you don't feel well, it was a matter you were ill and that was it you weren't going to get better. As now you've got the heart , you've got the chance of getting better improving all the time, but beforehand there was no bitterness it was just downhill all the time. Instead of heading towards the light at the end of the tunnel you were going away from it, as now you are going towards and it's a big difference because towards the end it was hopeless. As now it is good, is marvelous you know it's terrific, it's amazing the chance, it's very difficult for me to describe how good the difference is between bad and just now. I was very emotional because I was alive again , it was very difficult to try to say to yourself one minute you were half well three quarters dead, well dead for sure, and now you've got a chance and your nails are pink whereas before it was blue because the pump wasn't pumping properly, and now it's been marvelous for me and getting better and better everyday. As I said there will be hiccups and there will be hurdles still to come but I don't care I'll get over it I don't worry "

Previous illness experience could be seen both positively and negatively from heart transplant recipients and consequently had an effect on their adjustment.

Patients often seemed to attribute their current situation to their health status prior to transplantation. For some patients the fact that they were ill prior to transplantation was understood as the reason for not being able to prepare themselves for what to expect after the operation, or failing to develop realistic expectations. For other patients the fact that they were ill prior to transplantation helped them to realize that their health had improved significantly after the transplantation.

5.2.2.3. Adequacy of preparation

Many patients in this study emphasized the role of medical staff in their preparation for the operation, and attributed to the preparation provided, the way they coped and adapted themselves in their postoperative life. Patients who admitted being well prepared felt grateful to the nurses and doctors; they seemed to accept problems more easily because they were prepared for what to expect, and they were generally satisfied with their postoperative life.

13/2 "I'm grateful for the nurses and the staff who really helped at the beginning they give you the encouragement and they tell you things that are likely to happen to you so when something happen you remember the nurse told you this might happen, or the doctor said this might be a possibility ".

The importance that was given to the preoperative preparation was discussed in the findings in the category four "Was I prepared for the heart transplantation?".

5.2.3. Social factors

5.2.3.1. Existence or lack of social support.

Social support, from both family and friends, was reported as playing an important role in a patient's ability to cope during the whole heart transplantation experience. It was not unusual for patients to form helpful relationships with the nurses and other health-care staff. The role of social support in coping was also described in the findings in the sixth category "Coping" where the "Acquiring social support" was described as one of the coping strategies used by heart transplant recipients, and also in the first category "Traumatic experience" where patients reported the important role that the family support plays in their adjustment to their postoperative life.

Social support has been studied extensively as a coping resource that can mitigate the adverse psychological effects of environmental stressors (Cohen & Syme, 1985; Duck & Silver, 1990; Sarason & Pierce, 1990; Vaux, 1990). Caplan (1974) stated that, social support can exert a major influence on a client's ability to cope with a chronic illness. An individual's coping responses during crises are influenced not only by his or her ego strength, but also by the quality of help and emotional support provided by the social network.

Social support and especially support from the family was found in this study to play an important role in helping heart transplant recipients to cope with the various demands in the postoperative period.

1/14 "One thing that you've got to get is support from your wife , your family, and at that time you take that as being a natural thing to expect but I would honestly say having been through it, I don't think you could do it on your own. My wife was really more part of me than what she ever was and I think that's important. I think you really got to be honest with yourself and say well, if you had to be on your own and to have cope with all the phone calls, visitation to the clinics and the disappointments and all the rest of it... I think I would have given up , I think you need somebody who can give you a wee bit or well fairly big inspiration and the will to go through with it , and I think at the end of the day that's got to be a big factor in your success".

According to Moos et al (1982), close personal relationships can help individuals obtain information necessary to make wise decisions, find emotional support for them, and secure reassurance about the problems they face.

There were cases when patients complained about losing friends through their illness. One patient reported that his friends of 40 years had stayed away since his diagnosis. The patient tried to explain this attitude as being consistent with a cultural trait, as he tried to explain that people in his area stayed away from families who experienced an illness or other serious problems. The literature (as was cited in the findings in the first category "Traumatic experience" about the bad support offered by family) suggested that despite the evident importance of social support, people who fall ill may actually receive less support from family members and friends (Wortman and Conway, 1985).

According to Kessler et al (1985), the severity of the recipient's problems, as well as his or her ability to cope with these problems, may also determine the amount of

support received. People are often threatened and made uncomfortable by those who have experienced a life crisis, particularly if they feel vulnerable to a similar fate. For this reason , the more severe the victim's problems, the more threatened, and therefore unsupportive, others may become. This suggests that those in greatest need of social support may be least likely to get it.

It was found in this study that patients often understood their spouses' behaviour as supportive when it took the form of reminding them about taking their medication, accompanying them to clinics or listening and talking about their problems. According to Abraham and Shanley (1992), the kind of social support most helpful to patients may depend upon their health problem and their role relationship with others. In studying cancer patients, for example, Dunkell-Schetter (1982) found that informational and emotional support was seen as most helpful.

A similar finding emerged in the literature (Brownell et al, 1978), that suggests that spousal support plays a significant role in influencing the patient's adherence to the medical regimen by increasing motivation and enhancing a perceived need to improve health. As the authors state, specific mechanisms by which spousal support influences a patient include providing physical assistance such as sharing of tasks; supplying material aid or resources; using behavioural modification techniques; and providing instruction or advice, social participation, and intimate interactions to allow for expression of feelings and personal concerns.

In the following example the absence of support both from his wife and friends seemed to play an important role in the patient's dissatisfaction with his post heart transplantation life.

11 "I was getting bad support from my wife and I would be better with no support than bad support....I think that put a little bit of extra stress onto me and I ended up here and I blame her for the whole thing....it's been an ordeal its been an experience and if I had a bit of hind sight I wouldn't have done it. I don't really have much else to live for. I've lost a lot of friends, a lot of them stayed away because of my illness, and that's hurts me quite a bit."

Thoits (1986) has suggested that social support can be conceptualized as "coping assistance". In attempting to support crisis victims, for example, others may provide advice as to how to behave, or may suggest new ways of interpreting the crisis. Yet there is emerging evidence that some suggestions for coping are regarded by the victims as annoying and unhelpful (Wortman et al, 1985). For example, as the author has reported, conversations that aroused interest in new activities, development of new friendships, or the resumption of old hobbies or occupations during the first three months after the death of a spouse were greeted with hostility. Similarly, there is evidence that individuals who find some meaning in stressful life experiences are able to cope more effectively with the event than those who are not (Silver, 1983). However, others' well-intentioned attempts to impart meaning (for example, by suggesting that the death of one's spouse was "God's will") often do not have beneficial effects. According to Wortman et al (1985), these unintended negative consequences of the social support are fairly common among victims of life crises. By enjoining a crisis victim to look on the bright side, for example, the supporter may lead the victim to feel that his feelings and behaviours are inappropriate. By offering advice or tangible aid, supporters may convey to recipients that they are incapable of handling their own problems.

It became apparent that attempts to provide support were sometimes experienced as unhelpful by the heart transplant recipients. More systematic research may be able to determine whether certain classes of behaviours presumed to be supportive are likely to contribute to subsequent distress and perceived as unhelpful.

5.3. Summary

A large number of coping strategies were found to be employed by recipients in this study. An attempt to classify these coping strategies was avoided. It was thought to be inappropriate to attempt to separate coping as effective or ineffective except in broad terms. For example reports of behaviours that are apparently beneficial may be so in the short-term but have long-term negative consequences.

What was found in this study to be important was the fact that whether the employment of a particular coping strategy would be proved useful or not, leading to satisfaction or dissatisfaction, seemed to depend on other factors (as discussed in 5.2.).

Health care professionals have an important role in identifying when stress is likely to occur, how to recognize signs of stress and the teaching of patients effective ways of coping. Consequently their work may centre usefully on supporting existing coping strategies or helping the person develop new strategies (Abraham & Shanley 1992). Increased understanding of the coping strategies used by heart transplant patients could provide indicators for the appropriate care of cardiac patients and a theoretical foundation for the education of care professionals. Nurses and other care professionals, in turn, could assist patients to modify their beliefs about the problems

involved in heart transplantation and develop attitudes and beliefs to meet the challenge of living with these problems. Intervention programmes might focus on lessening the prevalence of a stressor, helping individuals avoid conditions that lead to stress, changing the appraisal of the situation, or providing information to alert individuals to the demands they will confront and to potential coping strategies for managing them.

Chapter 6: That's a small price to pay for being alive Vs Too big a price to pay for being alive.

6.0. Introduction to the Core Category

The category "That's a small price to pay for being alive Vs Too big a price to pay for being alive" concerned patients' perceptions of the heart transplant experience as a whole. Different interpretations were found in the data; Patients who were satisfied with the experience; patients who were satisfied with some reservations; and patients who were dissatisfied. There were patients who admitted that they were unreservedly satisfied or others who had some reservations, but because of the improved quality of life or of the importance of being alive, they accepted the problems as "that's a small price to pay for being alive". On the other hand there were patients who were dissatisfied and even regretted having undergone the heart transplantation admitting "that's too big a price to pay for being alive".

The category "That's a small price to pay for being alive Vs Too big a price to pay for being alive" represented the core category that emerged in the analysis of data and was the main theme around which other categories were integrated.

The core category in this study was identified following: considerable deliberation; further intense scrutiny of the data; consultation and reference to the literature; constantly reflecting upon what the common element or "root" of the process might be, in the way recipients experienced heart transplantation. The core category "That's a small price for being alive Vs Too Big a price" emerged representing patients' satisfaction and dissatisfaction with the heart transplant

experience, that is the outcome of the heart transplant crisis. The factors that were found to affect the outcome and made patients either satisfied or dissatisfied are discussed broadly in the Discussion Chapter 7.1.3 and in Chapter 5.2).

As Hutchinson (1986) states, the discovery of a core variable is an essential requirement to theory generation for a quality grounded theory study. Continuous reference to the data, combined with rigorous analytical thinking, eventually yields such a variable. The core variable becomes the basis for the generation of the theory. The categories, properties, phases, and dimensions of the theory are inextricably related to the core variable. The integration and density of the theory are dependent on the discovery of a significant core variable.

The core category in this study evolved by linking categories together. It represented the central phenomenon of this study; that is an explanation as to how patients felt in the post-transplantation period. The core category was the category which appeared most frequently in the data. It was fully saturated. It was found to account for a large percentage of variation in the pattern of patients' behaviour; and it was clearly related to the majority of other categories.

6.1. A small price to pay for being alive

A small price to pay: This category concerned patients' satisfaction with the heart transplant experience post-operatively.

4/7"... my feet are swelling and I find that went a size bigger in shoes just wearing floppy shoes....but that's nothing that's a small price to pay for being alive".

39/10 "Well if you are ever in a condition and you need one go for a heart transplant that's what I always say, definitely its marvelous even with all the side effects".

4/4 "I feel great in myself about getting a transplant, prior to this I was virtually dying on my feet so the transplant has given me a new life, a new start in life so I'm quite proud of the fact".

14/1 "If I was going to get it again I would do it again".

14/7 "If they asked, offered it to me again I would say yes, I would take it again no problem".

5/2 "I would go through it again tomorrow just now I really would, I don't find any problems everything is great like in the gardens rosy, but I'm prepared for everything no matter what the snag is ,because its five months since I've had the transplant or I would have been dead, so I always look forward I never look backwards and the light at the end of the tunnel is getting brighter and brighter all the time and there is no problem".

4/9 "Life is when you waken up in the morning its a bonus that you are still here so that's it".

14/8 "I just look at every day as a bonus, I just wake up every morning and you say well I'm still living my heart still ticking over".

6/10 "The fact that you realize you are alive it's great , you just look on every day as a bonus. I made a particular point of going back to the hospital afterwards just to see them in the ward that looked after me, just to see the look on their faces.....I just walked in and said "see what you've saved!!!" you know and they were so pleased as well to see a success, because I'm quite sure they must lost a few patients over the years....it was quite a thing for them".

16/1 "I think it's when you waken in the morning and you just say, another day thank God, it's a bonus-I've got quite a few problems so I canny say that I am a lot better but I've still been well worth it, it's been worth it 200 times better than what I was before, but there are lots of complications caused through drugs, I've got pains in my back and chest and I take a lot of pain killers for it- but everybody, there's a lot of them have had trouble with their back- but other than that I'm fine- my legs are a little bit weak but they're getting better, you just feel you are so lucky to have to get a chance, plenty."

5/4 "I was been given the gift of life and now it's marvelous".

13/5 "I'll always be grateful that I got the opportunity, and I got the operation and I'm really pleased and I hope that I can help other people I just hope that somewhere along the line...and help other people the way that I've been helped....it's a second chance and I hope I do better the second time round than I did the first time round, be a bit more sympathetic to people and- I think being so close to death as I was before the operation it makes you a wee bit more aware of

life and people were good to me, they were so considerate and I just hope that I can be a better person you know maybe be a bit more considerate to other people .....I've a second chance to do this."

Strong feelings of gratitude towards the surgeons and affection towards the nursing and medical staff accompanied the desire to help others as repayment for what they have received and the willingness to assist a patient who has been admitted for assessment. The strength of these feelings was expressed in a desire to explore new careers such as the church, social work, or even medicine. For so long the patient had felt at the receiving end of society and now he/she wished to put the new energies and emotions into giving. This phase could be allowed to level off without being unrealistically encouraged or discouraged. The return home and the gradual resumption of normal life restored stability but many patients continued to gain satisfaction from helping other heart transplant patients, by raising funds for the Transplant Centre and by promoting heart transplantation.

14/6 "The first month I thought I was in wonderland, it was really good, you could go for a walk and I wasn't very breathless, I could walk round about the buildings.....".

6/14 "They really gave me a quality of life I mean I'm back playing golf, driving, playing about with my family and doing things maybe slightly limited but generally speaking I've got a quality of life that no way I could have expected to have if I hadn't had got the operation".

14/7 " I'm still living and the job they've done on me was perfect, my heart is running perfect".

6/4 "I'm really pretty good and very thankful that they were able to do something for me".

14/1 "The treatment you get in here is first class, the nurses in here after the operation they come and have a talk with you and they put you in the what's going to happen and all the different reactions you have".

There were some patients who were totally satisfied without any reservations reporting no significant problems, feeling grateful for the fact that they are still alive and for the second chance of life that they were given.

13/3 "It's like a new life, it's a second chance, where everything is more precious, time you spend with your family and friends, Birthdays, Christmases".

16/2 "It's been great, the best thing that ever happened to me and just saved my life completely because I couldn't breath before, look at me now I'm getting about and I'm quite happy about that, it's given me another chance in life which if I couldn't have got, I wouldn't been here."

In the first example above (13/3) of a person expressing satisfaction, it could be interpreted in that the outcome (satisfaction) was influenced by the perception of the situation (he appraised the situation as being like a new life and as a second chance) and how his perception of the situation had influenced his way of coping (for example, *thinking positively* when he described that everything was more precious now). Another way of seeing this example of how this patient arrived at this outcome of 'being satisfied' was to understand that personal factors (for example, how he values family and friends and time spending with them) could influence his

perception of the situation (as being a new life and a second chance) and then how his perception could influence the outcome (satisfaction).

The second example (16/2) could be interpreted as how the coping (either *comparing* his health with how was before the operation and *thinking positively,* ie. seeing the bright sight of the situation, namely his improved health, or *rationalizing*, admitting that if he wouldn't have this operation he wouldn't be here) could influence the outcome (so he was happy and he saw the experience as the best thing that ever happened to him).

Another way to understand the process of arriving at this outcome was to understand that there were some factors influencing that process. In this case an illness-related factor (*previous illness experience*, i.e. the fact that he was breathless before the operation) could be seen as a factor influencing his perception of the situation (as being the best thing ever happened to him because it changed his life completely) and then consequently the outcome. In some cases patients who were ill before the operation and suffered from many symptoms that their heart condition caused, were more likely to be satisfied post-operatively because of the improved health they enjoyed as compared with those patients who did not have any symptoms before and now had to experience problems caused by the side-effects of the medication. How ill patients felt before the operation or asymptomatic was a factor that played an important role in creating expectations.

There were some other patients who expressed satisfaction, though with some reservations. They had to face many problems.

9/1 "I had osteoporosis the year before and fractured my spine twice, and I was admitted for 6 weeks and I couldn't play any more golf, I've had shingles in my head which is worse than the transplant....but you take these things as they come and accept them and just get on with life because you are still alive. I've got grandchildren along the road that I would have never seen if I didn't have my transplant".

1/3 "I'm quite happy the way I'm now, it was difficult very difficult at the time, but now whether it's because you get used with it or you are in a routine....I know what to expect and I do not worry about anything, I just take it as it comes".

The example 9/1 could be seen as how the coping process could influence the outcome, so even though there were indications (quite a lot of problems that were appraised as worse than the transplant itself) of a maladaptive outcome, the outcome appeared to be satisfaction with some reservations. The coping strategies she employed (*acceptance* of the problems) and personal factors (for example, *values in life*- how she valued her grandchildren) helped her to get on with her life and to appreciate the fact that she was still alive. She weighed the cost against the benefit.

In the example 1/3, the coping (*acceptance* of the problems) seemed to play an important role in the outcome (the patients is happy now), but personal factors *(prior coping efforts*-the patient admitted that he was got used with it because he had to cope with these problems earlier) seemed to influence the coping process as well.

6.2. Too big a price to pay for being alive

Too big a price to pay for being alive: represented patients' dissatisfaction with the new reality after the heart transplant that was expressed sometimes even with regrets of having undergone the operation.

11/5 "It's been an ordeal, it's been an experience as I said if I've had a bit of hind sight I wouldn't have done it"

Patients who were found to be dissatisfied tended to see the heart transplantation as the "exchange of one problem with another".

14/6 "Well it was nice to get a new life again but I was a little bit disappointed.... I could walk maybe 2 miles or so and I could run up the stairs which I couldn't quite a while before but then I took a virus what they call CMV virus and ever since I've really went down hill and I was quite disappointed after you know I mean for that first month or so really good and then just deteriorating after it".

30/10 "I've got more problems now than what I had before that, I never had problems with my back , before I could walk down the street and come back without any bother, and now I can hardly walk anywhere and that's causing trouble".

28/4 "And then not being able to be in control....it was out of my hands you know always sick and I thought oh this is awful I really felt one day, either cure me or kill me, because I'm so fed up feeling ill...".

There were dissatisfied patients who saw the experience as being traumatic, having to deal with a range of problems, and who found it difficult to cope. Some transplant patients even arrived at the stage of regretting having undergone the heart transplantation.

11/5 "I eventually got one heart and I'm very thankful for it but its been an ordeal, its been a traumatic experience, if I've had a bit of hind sight I wouldn't have done it".

11/1 "I was having quite a bit of problem with my chest and I got the feeling that nobody was listening to me too much because they didnae do anything about it and I was left to suffer pain for many many months, its only recently that's roughly about a year to a year and a half that this pain has started to ease off .They had playing about with drugs and things and its only two months since they took another drug back off me and subsequently this must have been a lot of the problem adding to the pain I was suffering from. I had an infection in my sternum of some kind and it was never treated and I had a year and a half with pretty rough time suffering bodily pain, joint pain, muscle pain, sore eyes. It was a year and a half after my operation when I was asked if I would do it again and I said no!".

The example 11/5 could be seen as how the patient's perception of the situation (he appraised the experience as being an ordeal and a traumatic experience) affected the outcome (dissatisfied and having regrets for having undergone the heart transplant).

In all the previous different types of outcome, it seemed that the outcome was influenced by the perception of the demands, by the coping strategies employed and

by other factors such as personal, illness-related and social. All these factors were discussed earlier in 5.2. How recipients perceived the demands that they have to face in the postoperative life, what coping strategies they employed, and what factors- personal, illness-related, and social- were present seemed to explain the differences in the outcome.

6.3. Summary

The differences in the outcome, as discussed above, directed the interest to what the factors, contributing to the outcome, might be. It seemed that it was not one factor that contributed to each outcome but rather a collaboration of several factors.

The outcome, how patients felt about the heart transplant experience post-operatively, was not independent of the demands that recipients had to face and the coping strategies employed. The outcome, as well as the demands, needed to be seen as part of the coping process. How patients appraised the heart transplantation and what significance they gave to the demands and what coping strategies they employed, were seen as factors affecting the outcome.

Demands were all those problems and changes that accompanied the heart transplant experience and patients needed to adjust themselves in order to cope with this difficult period post-operatively. Demands included the physical, psychological, family and financial problems, problems with hospitalization, changes in attitude and life-style, and psychological problems in accepting the donor's heart. Patients had to confront reality and respond to the situation, in order to cope with the physical weakness, role transition in the family, finding a job, and accepting the new heart. Psychologically patients had to deal with powerful emotions, such as a sense of

failure and self-blame, anger and grief in the face of the tension and fear that were linked to the uncertainty of the outcome, as presented in Chapter 3.

It was found in this study, that the demands that accompanied the heart transplant experience, were appraised as either stressful events with the potential of harming or as being positive for the patients' well-being. There were patients who appraised the demands as problems with only negative consequences for their lives. On the other hand, other patients appraised the same demands as not major problems as they were part of the "gift of life" they were being given.

In the first case, when the situation was appraised by patients as harm or threat for their lives, this was characterized by negative emotions such as fear, anxiety and anger. Patients were not convicted that they could successfully execute the behaviour required to produce a desirable outcome. This also affected the employment of particular coping strategies.

When the situation was appraised as a positive event, patients might have focused on the potential for gain or growth inherent in the event and these events may have been characterized by pleasurable emotions such as eagerness, excitement, and exhilaration. When demands were seen as "part and parcel" of the operation which is meant to improve recipients' health and their quality of life, acceptance of the demands involved, made patients satisfied for still being alive and for the "second chance" they were given.

CHAPTER 7: Discussion of the findings and development of the theory.

7.0. Introduction

This chapter deals with the discussion of the findings of the study. A description of the relationship found between the four main categories and how these categories are related and contribute to the development of the theory is given. How the theory "Price to pay for being alive: Coping with the postoperative demands in Heart Transplantation" was developed and its contribution to Nursing Theory and Practice is explained. The chapter also includes an evaluation of the study and a critique of the theory. Areas for further research and the limitations of the study are included.

7.1. Discussion of the findings

7.1.1. Relationships of the categories

The core category "That's a small price for being alive Vs Too Big a price" represented the central phenomenon derived from the data; that was patients' satisfaction and dissatisfaction with the heart transplant experience. The categories were defined, developed, and integrated, and gradually were related to the core category by means of paradigm-conditions, context, strategies, and consequences.

The categories "Traumatic experience" (presented in Chapter 3) and "Somebody else's heart in side me" (presented in Chapter 4) were found to reflect the most

common problems experienced and the changes which occurred during recipients' adjustment to postoperative life. The category "Coping" (presented in Chapter 5) was found to represent the various coping strategies employed to deal with these problems. The core category "That's a small price for being alive Vs Too Big a price" (presented in Chapter 6) was found to represent patients' satisfaction and dissatisfaction with the heart transplant experience; that is the outcome of the coping process with the problems experienced post-operatively.

7.1.2. Differences in the outcome.

Analyzing the data, it was found that there were different descriptions used by recipients in reporting the heart transplant experience and differences among recipients in the amount and type of stress that was experienced from heart transplant crisis. Recipients were classified as 'dissatisfied patients' and 'satisfied patients'. In the area of satisfaction, there were some recipients reporting total satisfaction without reservation and some others reporting satisfaction with some reservations. Heart Transplantation, even though is seen as the therapeutic procedure that prolongs life and improves health for the patients with end-stage heart diseases, is not always accompanied by satisfaction. In some cases the transplant was followed by great disappointment expressed with regrets of having the operation. These recipients saw the transplant as a trade-off, curing the heart problem but creating new problems to cope with. The "Price to pay" reflected the benefit and the costs of heart transplantation as described by patients. For some it was a "Small price to pay for being alive" while for others it was "Too big a price to pay for being alive" and often expressed regrets in undergoing the procedure.

A similar way of classifying the outcome was made by Artinian (1989) who concluded that the outcome of a life crisis can be a healthy adaptation that promotes personal growth or maladaptive response that foreshadows psychological problem. In this study the outcome was found to be either adaptation/satisfaction or maladaptation/dissatisfaction.

7.1.3. Factors contributing to the outcome

Although recipients' perception of the demands and ways of coping used were found to influence the outcome, there were some other factors, such as personal, social and illness-related that were found to affect coping and outcome by influencing patients' perception of their situation (as it was shown broadly in 5.2).

7.1.3.1. The role of the perception of the demands in influencing the outcome.

The perception, the meaning that was attached to the demands by heart transplant recipients in this study, was found to influence coping and adjustment in postoperative life. Whether patients perceived the heart transplantation as a "second chance" and "the gift of life" or as an "exchange of one problem with another", seemed to play an important role in determining the coping strategies they employed and whether they were satisfied or dissatisfied with their postoperative life (as discussed in Chapter 6).

According to Lazarus et al (1974) it is not the nature of an illness that is of uppermost importance, but rather the individual's cognitive appraisal of it. Miller (1986) stated that, if an illness is viewed as significant, heightened anxiety and depression are more likely to manifest themselves in an attempt to cope; if the illness is appraised as insignificant, the client will feel less personally threatened and will have greater energy for dealing with the problems presented by the illness.

Findings from this study about the role of perception in influencing the outcome found support in the literature. According to Lazarus and his colleagues (1966; 1984;) the outcome of a stressful transaction is mediated by appraisal and coping. Lazarus et al (Folkman et al., 1979; Lazarus, 1966; Lazarus et al., 1970, 1974; Lazarus and Launier, 1978) ascribe great importance to appraisal and consider it the critical determinant of the coping process.

As Heim et al (1986) state regarding the issue of coping, it is important to clarify the perspective one adopts, since the goals and the achievement criteria of coping may be quite different, even conflicting, depending upon the point of view adopted.

7.1.3.2. The role of coping in influencing the outcome

It was found in this study that the outcome, namely the way recipients appraised their heart transplant experience post-operatively, depended very much on how these patients coped with the various demands that accompanied the post-transplantation period. What was found to be of great importance in this study was that the selection of available coping strategies very much depended on how patients appraised the

problems (as discussed in Chapter 6) and on other factors that were present at the time of the selection of a particular coping strategy (as discussed in 5.2).

Any attempt to name ways of coping as negative or positive was avoided in this study because it was quite clear that the same ways of coping chosen by different patients had different effects. For example, talking to other heart transplant fellows was for some patients very helpful while for others, it resulted in considerable distress. While many patients seemed to talk considerably about the donor and the donor's heart, others found this to be anxiety-producing and avoided any conversation about this subject. So what was found to be helpful for some patients, was distressing for others. This is consistent with Lazarus' (1966) opinion that coping efforts that are successful for one person might have no effect, or be detrimental for others.

An example of why judgments about the effectiveness of coping strategies are likely to be inaccurate, is the use of denial as a coping strategy which can be both adaptive and maladaptive, depending on certain situations and/or at certain stages of an encounter. From the data collected, it was found that patients denied feelings toward the transplantation, the new heart and the donor. This finding is supported in the literature (Mai, 1986). This "graft and donor denial" may not be maladaptive but rather may be an aid in emotional adjustment. Patients need time to grief and think and organize how they can cope with the rigors of the heart transplant protocol. Denial may give the needed time for grief and make the emotional adjustment easier (Mai, 1986).

According to Kessler et al (1985), although it is widely assumed that an appropriate choice of coping strategies can ameliorate the impact of stressful

experiences, there is surprisingly little sound, empirical research bearing on this assumption.

7.1.4. Factors influencing the coping process

It was found in this study that heart transplant recipients' cognitive appraisal, definition of the demands involved, and the selection and effectiveness of relevant coping strategies were influenced by other factors. From the data analysis, and supported by research findings, values in life and value on life, patients' expectations and previous coping experience were found to be personal factors influencing recipients coping with the demands in the postoperative period. Present state of the illness, previous illness experience and adequacy of preparation, were seen as illness-related factors influencing the coping process. The existence or lack of social support also emerged as a factor that influenced the coping process. All these factors, as described previously in 5.2, played an important role in influencing the coping process and the outcome of the heart transplant crisis (as shown in figure 1.).

These factors (described broadly in 5.2) were classified as personal, illness-related, and social factors. These findings are consistent with findings in the literature that the coping ability of a patient is influenced by several factors, including: personality, specific significance of the illness phase, previous illness experiences, available external support (Heim et al, 1986 and Kuhn et al, 1988).

7.1.5. Summary

The ultimate aim of this study was to increase knowledge about the patient's process of adaptation to post-transplantation life, thus enabling health care professionals to better support patients in their coping and their adjustment to postoperative life. According to Larsson et al (1994), a patient's ability to profit from the treatment is influenced by his or her coping capacity.

Exploration of the coping process through which patients adjusted to the stressful situation of heart transplantation (Evans et al, 1984; Lough et al, 1985; McAleer et al, 1985,Wallwork & Caine, 1985; Mishel & Murdaugh, 1987; Kraft, 1971; Molish et al., 1971; Christopherson et al., 1976) typically focused on the end result of a patient's adjustment to a stressful situation while ignoring the details or processes of the stress and coping strategies of the heart transplant patients.

For one to have a better understanding of the reactions and adjustment of this group of patients, a more systematic discussion of the difficulties they face, and the way they cope with these difficulties, was needed. By understanding the problems experienced and coping strategies used, health care providers may help recipients' adaptation to the postoperative period and consequently improve the quality of life of heart transplant recipients.

7.2. Development of the theory

7.2.1. The theory "Price to pay for being alive: Coping with the post-operative demands in Heart Transplantation".

The study has suggested that the experience of heart transplantation can be explained by the theory of "Price to pay for being alive: Coping with the post-operative demands in Heart Transplantation".

The goal of the theory "Price to pay for being alive: Coping with the post-operative demands in Heart Transplantation" is the assessment and subsequent prediction by health care providers of the patient's ability to accommodate and to adjust to the changes and the demands that result from the crisis. Although it is difficult to predict with certainty an individual's ability to handle this kind of stress, the theory is based on the assumption that patients' perceptions of the demands involved in heart transplantation play an important role as to whether patients experience an adaptive or maladaptive outcome. The theory explains how factors like personal, illness-related and social influence the patient's perception. The theory also explains how these factors together with the patient's perception influence the coping strategies that patients employ in order to deal with these demands. The theory also offers a description of the concepts involved in coping and an explanation of the relationship among the concepts.

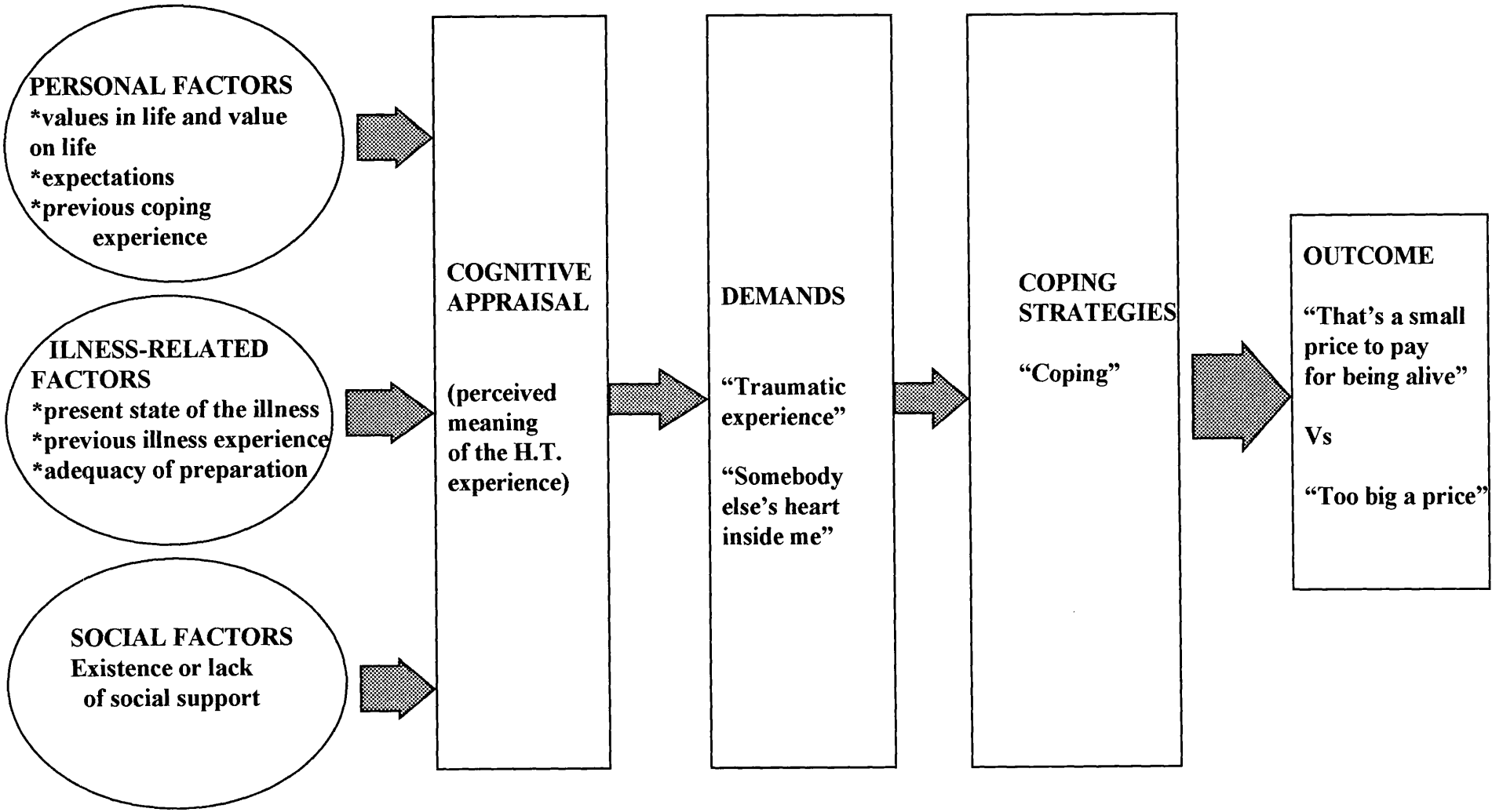

Figure 1. A conceptual framework for understanding the Heart Transplanat crisis, explaning the theory of "Price to pay for being alive: Coping with the post-operative demands in Heart Transplantation".

The theory "Price to pay for being alive: Coping with the post-operative demands in Heart Transplantation" offers an extension of Moos' Crisis Theory, and applies his basic concepts of major life crises and transitions (see also 1.3.), with adaptations, to heart transplant patients. One such adaptation is the assertion that the factors that influence how adaptively an individual copes with a heart transplant crisis, are different from any other health crisis.

The conceptual framework (as explained in Figure 1) was developed to explain the theory and indicates a sequential relationship of the categories developed. The emerging framework from this study describes recipients' perceptions of the heart transplant experience post-operatively; that is the outcome of the heart transplant crisis and characterized by satisfaction or dissatisfaction. The outcome of the heart transplant crisis is described through the formation of the core variable "That's a small price to pay for being alive Vs Too big a price". The conceptual framework of the theory "Price to pay for being alive: Coping with the post-operative demands in Heart Transplantation" explains how the outcome is influenced by the coping process; namely the perceived meaning that is attached to the postoperative demands and the coping strategies employed. The coping process refers to all those cognitive and behavioural efforts that patients do in order to adjust in the post-transplantation period. The framework emphasizes that individuals' cognitive appraisal, definition of demands, and selection of coping strategies are influenced by the person, by aspects of the heart transplantation, and by the social environment.

Because of major complications from the side effects of the use of chronic immunosuppression and the sensitive issues concerned the acceptance of the donor's heart, the heart transplantation crisis involves unique demands compared with other health crises. Moos' Crisis Theory (1977) was unable to account for the data of this

study as the demands involved in heart transplantation, the coping strategies employed and all the factors that influenced the coping process, were found to be different from any other health crisis. The demands involved in the post heart transplant period are different from any other health crisis and are tasks that entail the management of stresses of chronic medication and of changes in physical functioning or appearance; role transition in the family; unemployment and financial problems; often clinic visit and various aspects of the hospital environment; concerns about the donor and the donor's heart and readjusting goals and expectations in light of changes brought by the heart transplantation. The categories "Traumatic experience" and "Somebody else's heart in side me" represented all those demands involved in recipients' postoperative life. According to the conceptual framework (figure 1.) the recipient's perception of these demands can influence the employment of particular coping strategies and consequently the outcome (as discussed in 7.1.3.1.).

According to the theory, the "Price to pay for being alive" the patient's outcome, is part of the coping process with the Heart Transplant Crisis. The outcome, how patients see and feel about the heart transplant experience post-operatively, could not be seen exclusive of the demands required and the coping strategies employed.

Patients, having undergone a heart transplantation, are expected to adapt themselves in a new reality characterized by various demands. "Demands" is the name given to describe all those problems that heart transplant patients have to face post-operatively: including physical and psychological problems, financial and family problems, thoughts about the donor and the new heart, and changes that occur in patients' life and life-style, personality, attitudes and feelings. Heart transplant patients, in order to deal with these demands, employ a set of coping strategies.

The conceptual framework of the theory "Price to pay for being alive: Coping with the post-operative demands in Heart Transplantation" emphasizes that an individual's cognitive appraisal, definition of demands, and selection of coping strategies are influenced by the person, by aspects of the heart transplantation, and by the social environment. This framework is useful for identifying foci for prevention programmes. Interventions can be directed at one or more of these sets of factors. For example, programmes may focus on lessening the prevalence of a stressor, helping individuals avoid conditions that lead to stress, changing the appraisal of the situation, or providing information to alert individuals to the demands they will confront and to potential coping strategies for managing them.

The purpose of this study was to better understand the experience of living with heart transplant, exploring problems that patients experience, and identifying coping strategies used by them. In addition the findings of the study has generated nursing practice theory that could guide nursing interventions with these patients. Nurses, taking into consideration that changing perception and coping effectively can alter the outcome from maladaptive to more adaptive, can intervene by helping patients to change distorted perceptions and use more effective coping strategies. More information and clarification from nurses may help the patients to redefine their difficulties.

7.3. A critique of the theory

7.3.1. Introduction

The grounded theory approach to data collection and analysis allowed a substantive theoretical perspective to be derived, which helps to explain heart transplant recipients' experience, and fulfilled (as shown in 7.3.2., 7.3.3., and 7.3.4.) Charmaz's (1990) and Glaser and Strauss' (1967) definitions of theory. Charmaz (1990) defines theory as something which, "Explicates phenomena, specifies concepts which categorize the relevant phenomena, explains relationships between the concepts, and provides a framework for making predictions" (p.1164); and Glaser and Strauss' (1967) definition of a theory. By theory, Glaser and Strauss mean: "A strategy for handling data in research, proving modes of conceptualization for describing and explaining".

Polit and Hungler's (1993) assessment of the characteristics of theory was also chosen as a framework to critique the theory of "Price to pay for being alive: Coping with the post-operative demands in Heart Transplantation", as their assessment provides a comprehensive and relevant account of theory definition. The critique examines the theory's ontological and practice contributions, and will be achieved using Polit and Hungler's (1991) headings, namely: Summarization of existing knowledge; Explanation of observations and prediction and control of outcomes; and, Stimulation of new discoveries.

Polit and Hungler (1993) contend that theoretical systems represent the highest and most advanced efforts of humans to understand the complexities of the world in which they live. There can be no doubt that the process of heart transplantation is a

complex and emotive procedure that involves major physical and psychological problems, as recipients have to deal with the complications from the side effects of the use of chronic immunosuppression and the sensitive issues that concern the loss of their own heart and the acceptance of the donor's heart. Parkes (1993) urged researchers not to shy away from exploring difficult and painful situations, as an essential reference is required, from which knowledge, understanding, and further research can gain stimulus, flourish, and continue to unravel the maze of human complexity.

7.3.2. Summarization of existing knowledge

According to Polit and Hungler (1993) theory allows the scientist to bring together observations and facts into an orderly system. Theories work as efficient mechanisms for drawing together and summarizing accumulated facts from separate and isolated investigations. The linkage of isolated findings into a coherent structure makes the body of accumulated knowledge more accessible and, therefore, useful to practitioners who seek to implement the findings and to researchers who seek to extend knowledge. As important is that theory must be congruent with the realities of the world, existing knowledge, and cultural values. Such demands have been amply demonstrated in the development of the Theory of "Price to pay for being alive".

Primarily, one of the exemplar contributions and strengths of the proposed theory is that it was developed from data provided from the 'emic' perspective of recipients' experience of the heart transplantation, narrated by them and reflecting

their world-view. Therefore, it is expected to have relevance to the study of other individuals in similar circumstances.

The theory derived from this study is firmly embedded within the traditional and prevailing contemporary culture of life and importance of life in Western society, and, more specifically, within British traditions of death (Rogers 1984). Rogers (1984) stated that a "psychological transplant" exists in addition to the organic, because patients often feel forced to accept some characteristics from the deceased donor.

Such a solid foundation provides a backdrop from which theoretical insights can be developed, such as patients' perceptions of the loss of their own heart and having it replaced by the donor's heart, and their concerns about the impact on their personality. Not only does the theory incorporate the heart transplantation and coping literature, but it fulfils another criterion of good theory: it draws on Moos' Crisis Theory (in 1.3.) to expand its explanatory power providing a major extension of Moos' Theory, applying the basic concepts with adaptation to heart transplant patients.

The theory "Price to pay for being alive" presents a unifying, coherent story in which other relevant studies have found strong support and representation, and which, in turn, has allowed them to illuminate its conceptual foundations. Particular care was taken to make use of British studies to link with this study; which provided its own insights. The effect of drawing together such a strong, supportive, logically, interrelated base has fulfilled yet another requirement of good theory; that is, to permit new statements about phenomena to be derived. For example theoretical concepts (in 1.4.5., 7.2., and 7.5) have been offered which underpin the importance

of the perceived need and benefit of feedback to health professionals involved in heart transplantation.

Complete theory, Polit and Hungler (1993) state, should indicate gaps in knowledge. The theory "Price to pay for being alive" has identified the lack of representation in the heart transplant literature and the absence of present theories on coping process in heart transplantation. It is argued that the proposed study has added an explanation to the literature of coping with a the Heart Transplantation Crisis. The theory points to broader areas of Heart Transplant recipients' needs and the way they cope with the post-operative demands. The theory stresses an emphasis on the unique demands (chapter 3 & 4) involved in the Heart Transplantation Crisis and are so different and demanding from any other Health Crises.

A quality theory, according to Hutchinson (1986), must possess relevance related to the core variable and its ability to explain the ongoing social processes in the action scene. In this study the theory explains how the outcome, recipients' satisfaction or dissatisfaction post-operatively (which is the core variable and presented in Chapter 6), is influenced by the coping process; that is the perceived meaning that is attached to the postoperative demands and the coping strategies employed. The theory also emphasizes that individuals' cognitive appraisal, definition of demands, and selection of coping strategies are influenced by the person, by aspects of the heart transplantation, and by the social environment (in 5.2).

The theory developed from this study raised questions about the support that recipients receive from their families (in 5.2.3.1) due to the inability or difficulty of the family to cope with the demands involved in heart transplantation. It therefore provides reasonable groundwork for continued research in the identification of the

needs and the coping of the family. It did place sufficient emphasis on the importance of support systems related to patients' adjustment to their post-operative life.

7.3.3. Explanation of observations and prediction and control of outcomes

Polit and Hungler (1993) comment that overall, the purpose of theory is to make scientific findings meaningful and generalisable. They suggest that theory guides the search for not only the *what* of phenomena but also the *why* of their existence. The power of theories to explain lies in their specification of which variables are related to one another and what the nature of that relationship is; and ultimately, theory provides a framework for prediction and control (Polit and Hungler, 1993).

These qualities are one of the major ontological contributions of the theory of "Price to pay for being alive" in that it explicates a foundational, comprehensive account of recipients' experience of heart transplantation, and that this is achieved within the particular social context of the UK. In doing so, the fundamental and structural requirements of theory, as stated by Polit and Hungler (1993), have been met. Namely, that conceptual explanations of the phenomena under scrutiny which constitute recipients' experiences, have been constructed to give a full account of the story. Not only has an explanation of these events been provided, but the core element of coping with the post-operative demands was identified, which makes the categories within the theory even more valid because of their integral cohesiveness and consistency.

Polit and Hungler (1993) further make the point that theory must ultimately provide useful accounts. It is argued that this is another major contribution of this

study's theory. Within the context of healthcare, the proposed theory provides a framework which could lend an insight and increased understanding of the problems involved in heart transplantation and make the coping process explicit. It also provides indicators for the appropriate care (see also 7.1.5. & 7.5.) of heart transplant recipients; and provides a fundamental point of reference for education, research and further theoretical development. Understanding the problems experienced and coping strategies used, health care providers may help recipients' adaptation to the postoperative period and consequently improve the quality of life of heart transplant recipients: by identifying the needs of recipients and areas where help need to be focused.

By explaining the process of coping in heart transplantation, the nature of the coping has been exposed and new light has been thrown on its interpretation. This is important since it promotes a means through which the cycle of care can be completed. Thus, recipients are able to achieve an improved quality of life and health care providers can receive closure, reinforcement and fulfillment of their professional roles. Also, the linking of these two theoretical perspectives explains the implicit role of the concept of care in this delicate situation and how it may be helpful to all involved.

The theory clearly shows the difficulties encountered during the heart transplant process. It is suggested that this would be helpful to both families and health care providers. By identifying these areas, it has demonstrated where help may be focused thus suggesting the likely outcome of future situations. Such understanding could contribute to the scope of knowledge and subsequent control of events surrounding heart transplantation. It could also be instrumental in helping to set standards and

guidelines for the care of heart transplant recipients and their significant others (see also 7.3.3., 7.5.& 7.6).

The theory developed in this study may be of particular value to nurses as they are taught to use conceptual frameworks to guide their work in the assessment, planning, implementing and evaluating of patients care. The theory could aid the development of an appropriate nursing care plan. The theory, by giving a discrete description of the heart transplant experience, provides nurses with a tool to perceive, organize, and predict their clinical care, giving them some control over the outcomes. The theory is useful for identifying foci for prevention programmes (see also 7.5). Interventions can be directed at one or more of these sets of factors. For example, programmes may focus on lessening the prevalence of a stressor, helping individuals avoid conditions that lead to stress, changing the appraisal of the situation, or providing information to alert individuals to the demands they will confront and to potential coping strategies for managing them. Nurses, taking into consideration that changing perception and coping effectively, can change the outcome from maladaptive to more adaptive, can intervene by helping patients to change distorted perceptions and use more effective coping strategies. More information and clarification from nurses may help patients to redefine their difficulties.

It is argued that the theory can facilitate identification of those patients at high risk of poor adaptation, evaluating the effectiveness with which patients will be able to cope with the changes and stress involved in heart transplantation. Although intervention has not been incorporated within the theory, the assessment of patients' coping could be used to suggest needed points of intervention. Interventions could be aimed at understanding how the person is experiencing the crisis, reinforcing

usual coping strategies, and assisting with resolving the crisis while learning new coping strategies.

The theory developed in this study provides nurses with a conceptual framework which may enhance the awareness of the needs, the problems and the ways of coping of heart transplant recipients. It could be used as a reflective framework for nurses to examine their own feelings about heart transplantation and all that it entails. According to Bailey and Clarke (1989), a thorough understanding of the concept of coping can help a nurse in his/her day-to-day work. First it may be important for health education by teaching the patient to cope. For those patients who have developed their own coping strategies, a knowledgeable nurse could give reinforcement and support.

The theory could be used as a basis for prediction as to how recipients coping with the heart transplant crisis can experience a healthy adaptation. For example, using this theory one could have a better understanding of what resources need to be available in the post-transplantation period in order to facilitate the coping process; and how likely it is that recipients will have a positive perception (see also 5.1.4. and 6.1.) of the heart transplantation and of the demands involved in the postoperative period to experience an adaptive outcome of the heart transplant crisis. According to Hutchinson (1986), a quality theory must work; it must explain the major behavioral and interactional variations of the substantive area. Such a theory can predict what will happen under certain conditions or given certain variables.

Therefore, the theory developed in this study can be used as a teaching instrument. Theories tend to be useful in helping students to grasp a set of ideas. They also, allow teachers a framework upon which to build their information and

channel students' experiences. Providing a particular perspective also has the advantage of potentially stimulating discussion, and facilitating constructive argument. The Theory has also a place in the training of heart transplant staff.

7.3.4. Stimulation of new discoveries

Polit and Hungler (1993) suggest that one of the fundamental contributions of any theory is its ability to generate new ideas and encourage and facilitate research. Theory will suggest the inferences and hypotheses which can be formulated from them, the direction and growth of research, and lends itself to replication and development.

A multidisciplinary approach, from disciplines such as psychology and sociology, has important contributions to make to the understanding of the heart transplantation process as already demonstrated in this work. For instance from a psychological perspective. Bunzel et al (1992) state, heart transplantation therefore is unique among all operations and cannot be compared to other transplantations. It involves a confrontation with symbolic and mythological concepts that are hard to fathom. Heart transplantation obviously is not simply a question of replacing an organ that no longer functions. Kuhn et al (1988) summed up their results and concluded that apparently no other procedure in medicine or surgery confronts patients with comparable emotional stress. Sociological analysis of organ recipients' long term reactions and adaptation suggests evidence regarding long-term mental health effects (Simmons & Anderson, 1982; Simmons et.al., 1987,1988).

To date, research about heart transplantation has focused on the end result of a patient's adjustment to a stressful situation while ignoring the details or processes of the stress and coping strategies of the heart transplant patients. However, this theory has provided fundamental information, from which a better understanding of the adjustment process can be facilitated.

The theory is dynamic in that it takes into account factors as values in recipients' lives described as playing an important role in influencing the coping process, are capable of changing. As new factors that influence the coping process are identified, new categories will be constructed or current categories will be modified to incorporate them. For example more or different personal or social factors may be found to influence the coping process, and can be incorporated into the theory. This fits well with Hutchinson's (1986) account of a quality theory, that it should be modifiable, as social life is not static and a quality theory must be able to capture its constantly fluctuating nature.

Clearly, there is still much to be explained about the coping process with the heart transplant experience. The theory may provide a framework for further investigations or a springboard for a more parsimonious explanation of the process. Other areas of research, emulating this study are elaborated in section 7.6.

7.4. Reflections on the study

This study attempted to explore the problems, physical and psychological, experienced and coping strategies used by heart transplant recipients. The needs of

heart transplant recipients were also explored by examination of the comments of patients about their problems.

It was intended that the use of Grounded Theory would allow exploration in great detail as to how recipients cope with their problems in the post-heart transplantation period. Systematic exploration of the way recipients cope with the demands in the postoperative period has not been undertaken before. The present study examined a range of factors affecting this coping process.

A major finding was that whether recipients were satisfied or dissatisfied post-operatively depended on the way they perceived the demands experienced in the postoperative period. Another notable finding was that the recipients' view of the heart transplant experience was "shaped" by their personal experiences, by aspects of the heart transplantation and by the social environment, as it was discussed broadly in the 'Discussion' chapter. Grounded theory provided the opportunity to explore the thinking and reasoning behind the recipient's view.

Having used only one research approach, grounded theory and interviews in this study, it is only possible to speculate about how this method stands up against other alternatives. Nevertheless, it does seem reasonable to suppose that a more structured method would not have yielded the kind of data obtained by the in-depth interviews. The researcher would not have opened up some of the areas which were eventually uncovered had the interview been more pre-determined. It is argued that the range of data and the opportunity to follow certain lines of inquiry and to drop others would not have been afforded by a more directed approach.

The fieldwork method employed in this study, it is contended, was successful in eliciting the recipients' views of the heart transplant experience. The informal, in-depth, un-structured and flexible approach using grounded theory allowed the recipients to raise topics which the researcher would not have thought to include in a more structured research design. This study then, has contributing to the knowledge and understanding of the coping process involved in the heart transplant crisis.

As it has been observed already, the analytic categories in this study were not discrete entities. There were many ambiguities, overlappings and interrelationships which, for clarity of presentation had to be resolved by producing distinct categories. However as there was no formal co-judging of qualitative categories, it should be remembered that the analysis offered, represents the interpretation of the researcher alone. Readers may judge for themselves on the basis of the evidence provided, whether or not this interpretation is convincing.

7.5 Implications of the theory for practice

According to Mishel and Murdaugh (1987), modern medicine has been termed a 'halfway technology' because no matter how wonderful, the sophisticated technology with its accompanying procedures does not completely cure illnesses. Instead, the major advances allow persons to live longer with their illness and perhaps enjoy a better quality of life. However, the medical perspective is not adequate for dealing with psychosocial issues emerging from transplantation or for assisting nurses to meet the psychosocial needs of patients waiting or following transplant surgery. As the authors suggest, substantive nursing theories that address major nursing practice problems must be developed.

The theory of "Price to pay for being alive: Coping with the postoperative demands" offers a new perspective of where help may be focused. The theory explains the coping process involved in heart transplant recipients' adjustment to the postoperative life. The theory may be used as a basis for prediction of how recipients coping with the heart transplant crisis can experience a healthy adaptation. For example, using this theory one can have a better understanding of what resources need to be available in the post-transplantation period in order to facilitate the coping process; and how likely is when recipients have a positive perception of the heart transplantation and of the demands involved in the postoperative period to experience an adaptive outcome of the heart transplant crisis.

Using the theory "Price to pay for being alive: Coping with the post-operative demands in Heart Transplantation" to conceptualize the heart transplant recipients' experience, leads to several possible guidelines for interventions. Interventions are aimed at understanding how the person is experiencing the crisis, reinforcing usual coping strategies, and assisting with resolving the crisis while learning new coping strategies.

According to Moos (1986), life transitions and crises confront a person with a critical juncture or turning point. Personal growth and an expanded repertoire of coping skills often follow the successful resolution of a crisis. But failure to manage a situation effectively may foreshadow impaired adjustment and problems in handling future transitions and crises. According to crisis theory (Moos, 1986), an individual is especially receptive to outside influence in a time of flux. Such accessibility offers nurses as well as family and friends a special opportunity to exert a constructive impact.

Nurses and caregivers who are mindful of the typical issues that arise in normative transitions and prevalent crises, such as heart transplant crisis, can prepare individuals and their families for the experiences they are likely to encounter and help them to expand their coping resources and repertoires. More generally, prevention programmes can teach individuals to recognize and reduce sources of stress and help them to strengthen their personal competence, coping skills, and social resources (Cowen, 1983). As Moos (1984) stated, the success of prevention programmes is closely linked to the caregivers ability to be responsive to the needs of those in crisis. Caregivers conversant with knowledge of coping tasks and skills and sensitive to people's emotional reactions and needs, can diffuse the negative impact of life's crises and nurture the potential for growth intrinsic in such situations.

The role of cognitive therapy (CT) (see also 1.4.5.), as an intervention in a heart transplant programme, can emphasize belief and attitude change as the fundamental process leading to effective coping with heart transplantation. Cognitive therapy allows the patient to reconceptualize life difficulties as solvable problems. It focuses on the patient learning a specific schema to assess and modify irrational, stress-inducing thoughts. In adapting CT to a heart transplant program two goals need to be identified:1) to teach patients about the influence of their thoughts on their emotions and behaviour, and 2) to present a simple formula that patients may use to identify and alter those irrational thoughts that have often resulted in unpleasant emotions and poor problem solving.

For example, for heart transplant recipients who complain about experiencing a lot of pain after the operation, CT intervention can help them to understand the important interrelationship among thoughts, stress, and pain. They can see that physical pain is only one source of their suffering. Other sources of distress in their

lives are separate from pain and are within their ability to manage. Some patients argue that pain is the only really negative aspect in their lives and it is the sole cause of their distress. It takes only minimal intervention to help these individuals to recognize that other factors, although they are perhaps aggravated by the pain, are upsetting them. Pain is but one stressor among many others.

A patient, for example, said that he and his wife are not getting along because the pain prevents him from helping around the house. He has concluded, therefore, that pain is the sole cause of marital arguments and his resulting anger and depression. The fallacy of this conclusion can be pointed out by asking the patient whether he and his wife ever argued before his operation. By asking these questions, the patient can realize that the problem that led to his frustration and depression was not just pain but rather a destructive pattern of communication between him and his wife that had existed prior to the development of the pain condition. Using this approach can help patient to understand that he could feel better even if his pain condition remained the same.

This approach can help patients to understand the important cognitive principle of the relativity of positive and negative feelings and situations. They can begin to realize that their lives were never free of all suffering before their heart transplantation. Thus, much of their recent unhappiness is the result of unrealistic expectations of themselves leading to frustration, anger, and depression.

Through CT approach, patients can begin to understand that a person's thoughts about situations determine his or her emotional and behavioural response to a particular situation, and the cognitive interpretation of the situation can be the true

cause of negative emotions and poor coping. Thus, the patient's irrational thoughts increased the likelihood of his suffering.

Simple examples of how heart transplant recipients' interpretations of the postoperative demands affect their emotional health, can serve as an excellent introduction to CT. These examples can clearly show how these interpretations are relative and vary from individual to individual. Certain thoughts lead to productive coping, whereas other thoughts may lead to unnecessary depression, anxiety, and anger. Patients benefit from understanding that they cannot directly control their emotions or their behaviour in any lasting, substantial way without first changing their thoughts. This process of reviewing habitual thought patterns fits well into the self-management model, since the patient is the best person to monitor his own thoughts. The patient need to be reminded that the CT process is ongoing and reflects a coping, rather than curative, perspective. No one ever thinks rationally all the time, nor would that be a reasonable goal for anyone. Thus, CT aims at identifying and changing recurrent irrational thought patterns that cause chronic negative emotions.

Irrational thoughts and distortions can be discussed with the patients and patients are encouraged to realize that they can exercise some control over their emotional health by altering the way they think. Every day examples of stressful events can be analyzed in terms of how these could be interpreted differently so as to minimize their stressful impact and maximize use of adaptive coping responses. Thus, pain experienced after the operation and physical weakness, can be put into a new perspective, making them one of many life stresses as opposed to the overwhelming life burden that is the cause of all the patient's misery. Further, CT reinforces for patients the awareness of their own responsibility for their well-being.

Patients can understand that negative emotions are not necessarily the result of distorted thinking. Anxiety, fear, sadness, and anger are normal and inevitable responses to many life events. Patients can learn how to discriminate between healthy and unhealthy expressions of these emotional states. Patients may need encouragement to develop more effective ways of coping with their negative emotions through constructive action in spite of the presence of negative emotions.

Even though it may be desirable to develop interventions to facilitate effective coping among those experiencing life crises, as in heart transplantation, it is worth considering whether intervention should be applied. There is evidence available from several sources (Weiss et al., 1976; Herrmann & Wortman 1984) that those who attempt to cope with their problems but are unsuccessful may suffer more deleterious consequences than those who do not even attempt to cope with their problems. As Menaghan (1983) states, moreover, such coping failures might initiate a "malignant spiral" in which poor coping results in greater role strain, which results in still more ineffective coping.

Intervention efforts to educate the patients, may focus on the individual's needs when choosing methods and prioritizing context. For example, data from this study suggested an important role of family in patients adjustment to postoperative life. For an individual patient, then, may be helpful to use examples that relate to this setting and explore issues in these domains. One of the problems that often was reported by patients was the inadequate preparation of the family for the heart transplantation. Consequently family members appeared to have difficulties in coping with the various demands and changes that heart transplantation brought to their lives. As a result often was reported by patients to receive bad support or no support at all from their family. But it is not of less importance that family members suffered

the consequences of the inadequate preparation and the difficulties in coping. Employing group process methods, rather than traditional lecture or one-on-one counseling may be useful in working through life circumstances that affect family relationships.

The purpose of this study was to better understand the experience of living with a heart transplant, exploring problems that patients experience, and identifying coping strategies used by them. Making the coping process explicit may contribute to an understanding of the problems involved in heart transplantation; for example, increased understanding of this process could provide indicators for the appropriate care of heart transplant recipients and a theoretical foundation for the education of care professionals (see also 7.1.5.). By understanding the problems experienced and coping strategies used, health care providers may better support recipients in their coping and help recipients to adapt in their postoperative life and consequently help them to achieve an improved quality of life. Nurses and other care professionals, in turn, can assist patients to modify their beliefs about heart transplantation and develop attitudes and beliefs to meet the challenge of living with continual unpredictability.

7.6. Areas for further research

Although the analysis in the present research was necessarily confined to the focus of the study, that is, to the heart transplant recipients' experience, the data suggested other lines of inquiry which would be worth investigating.

Further work may be useful to test the theory developed in this study with populations other than heart transplant recipients. Quantitative approaches may be used to explore the broader applicability of the concepts of the theory developed in this study.

The theory provides reasonable groundwork for continued research with populations about which little is known, not only in relation to the psychological well-being of the patient but also of the family of the recipients and particularly of their coping. Watson (1987) supports the position that when an adult family member becomes disabled, the entire family is affected by the experience. An adaptive family that is able to contribute to the rehabilitation process results in a more favourable outcome for the patient (Watson, 1987).

Another area of study is the identification of needs of significant others. As a source of support, family members contribute significantly to a successful recovery (Watson, 1987). Determining their specific needs or concerns during this critical period allows assessment of coping skills and abilities to adjust to an altered life-style after transplantation.

The findings of this study served to describe the nature of spousal supportive behaviours that influence the heart transplant patient's coping, as perceived by the patient. The study did not measure spousal support. It did place sufficient emphasis on the importance of support systems related to patients' adjustment to their postoperative life to merit additional research in this area. Further research would be helpful to determine which spousal behaviours are perceived by the spouses themselves as supportive. A study of this nature might also address what types of

coping strategies are incorporated by the spouses to remain supportive to the patient.

Another area worthy of additional investigation involves the finding that particular factors such as personal, illness-related and social, influence the coping process in the postoperative heart transplant period, as it was investigated in this study from one month up to three years. Research that investigates the effect of other factors in this coping process would also be valuable. While it appears that some personal characteristics are related with coping, there is a need for more personal characteristics to be adequately identified and studied.

7.7. Limitations of the study

The recruitment of the sample for this study could be seen as one of the limitations as the subjects constituted virtually a mono-cultural group, as all were white Scots. As it has been stated, the group of recipients interviewed in this study can not be held to be a representative group. This sample was obtained for interview in the spirit of Glaser and Strauss' (1967) "theoretical sampling" and not in any statistical sense. Although the volunteers, by definition, were not selected by any recognized sampling method which would enable the results to be generalized to a wider group of heart transplant recipients, the data are intrinsically worthwhile because they represent a freely given account of the heart transplant recipients' world.

All respondents were given a choice about taking part in the study. But those that agreed to take part may represent a self-selected group which had strongly positive

or negative comments to make about the heart transplant experience. It is unknown how typical of other available recipients this group is.

Another source of bias in the data, lies in the fact that all the patients were currently receiving care. This may have inhibited the recipients from criticizing all those problems that are involved to the treatment and the care received, despite assurances being given about their treatment not being affected and that they could withdraw from the study at any time.

Another weakness in the theoretical construction is that participants were interviewed only once. Heart transplant recipients' needs and perceptions of their experiences could change over time. However, this study was unable to account for such inquires because time constraints limited data collection to a cross-sectional approach. Further research could use the theory to examine recipients' problems and ways of coping using a longitudinal investigation. Using a longitudinal design could provide an opportunity for exploring the development of heart transplant recipients' coping strategies over the longer term.

Along with recognition of the above limitations it should be acknowledged that information obtained about some phases of the subject's experience is retrospective in nature and is limited by the subject's recall of the events.

According to Morse (1994), the quality of the research outcomes is, therefore, dependent upon the quality of understanding that the researcher is able to develop throughout the course of the research about the subject of inquiry. Morse (1994) stresses the centrality of the extensive, cognitive engagement and resources deployed by the researcher when developing a grounded theory. However, Morse (1994)

explains that whatever the qualities of the research, the researcher, seeking understanding, is limited to an approach that consists of a number of restrictions. In the first instance, the researcher is limited by personal, subconscious perceptions, which will influence what is observed, recorded, developed or stressed as part of the research process. Indeed, some of these subconscious elements may be bound up in sociocultural and life experience, as well as the minute fluctuations that take place constantly within the individual. Another problem is the often idiosyncratic way of managing the data to facilitate the emergence of new perspectives (Morse. 1994).

Bearing these requirements in mind, there can be no doubt about bias in interpreting and understanding phenomena in this study caused by the personality and sociocultural and life experiences of the researcher, who is a foreign student and the English language is not the mother tongue.

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RESEARCH ETHICS COMMITTEE

Chairman: Mr Colin Buck
Secretary: Mr Iain Douglas, Administration

Royal Infirmary
84 Castle Street
Glasgow G4 0SF

Telephone 041 552 3535
Fax 041 304 4889

If Phoning Ask For:
Sharon - ext 4020

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6th February 1995

Professor D Wheatley
Cardiac Surgery
Glasgow Royal Infirmary

Dear Professor Wheatley,

Research Ethics Committee - Submission:

The identification of the problems, physical and psychological that patients undergoing heart transplantation and their families experience after the heart transplantation on the coping strategies used by them

I am now pleased to advise you that, at the February meeting of the Research Ethics Committee, this project was approved. The Patient Information and Consent form and any protocols submitted with the project have also been approved.

The study must be undertaken within two years of the date of this letter. After that time approval will be deemed to have lapsed and the project will require to be resubmitted. Please note that approval is conditional upon a report being submitted to the Research Ethics Committee. For this purpose, a pro-forma questionnaire will be forwarded to you in approximately one years time.

Trust Board approval is also given, as there are no substantial financial implications. I should be grateful if you would ensure that relevant senior nursing staff are informed about the study when in-patients are involved.

You may therefore take it that the application has been approved on behalf of the Research Ethics Committee and the Trust Board and you may proceed.

Yours sincerely,

Iain Douglas
Secretary

APPENDIX 2

Dear Mr .....

My name is Evridiki Kaba, and I am at present undertaking a study at the University of Glasgow, Department of Nursing Studies, under the supervision of Dr. Eamon Shanley.

The purpose of this research study is to identify the problems and the coping strategies used by patients and their family after a heart transplant.

It is hoped that the study of coping strategies may enable health care professionals to help patients and family deal more effectively with problems encountered.

Your participation in this study would be appreciated. The study involves taking part in an interview which will last about 35-45 minutes.

Interviews with transplant patients will be planned to coincide with their visits to the clinic. The content of the interviews will be treated in strict confidence.

I hope you are willing to take part in the project. If you agree I would be grateful if you could sign the attached consent form. I would appreciate if you could return it to me by 24th of March, using the stamped addressed envelope provided.

I would be pleased to give you further information if you so wish.

Yours sincerely

Evridiki Kaba..... Dr Eamon Shanley

APPENDIX 3

Dear Mr .....

I am conducting a study to look at problems experienced by patients who have undergone a cardiac transplant and the ways of coping used by them. The aim by the study is to identify methods of helping patients deal with problems more effectively.

The study involves interviewing patients and family members. All information collected will be used solely for the research project and will treated confidentially.

If you do not want to take part in the research project or at any time you wish to stop taking part you may do so. The care which you are presently receiving will not be affected in any way.

CONSENT

I(name).....of(address).....

.....

.....

agree to take part in the Research Project described above.

Evridiki Kaba has explained to me what I have to do, how it might affect me and the purpose of the Research Project.

Signed.....Date.....

Witness.....Date.....